## AMERICAN HEALTH INFORMATION

## **COMMUNITY MEETING**

# March 7, 2006

Hubert H. Humphrey Building 200 Independence Avenue, SW, Room 800 Washington, DC 20201

## **List of Participants:**

- Secretary Michael O. Leavitt, Chair
- David Brailer, MD
- Craig Barrett, PhD
- Gail McGrath (representing Nancy Davenport-Ennis)
- Lillee Smith Gelinas, RN
- Douglas Henley, MD
- Howard Isenstein and Chantal Worzala (representing Charles Kahn, III)
- Julie Gerberding, MD (also represented by Edward Sondik)
- Kevin Hutchinson
- Mark McClellan, MD, PhD (also represented by Tony Trenkle)
- Michelle O'Neill
- Jonathan Perlin, MD, PhD
- David Ayre (representing Steve Reinemund)
- E. Mitch Roob, MD
- Scott Serota
- Linda Springer (also represented by Daniel Green)
- Mark Warshawsky, PhD (also represented by Adele Morris)
- William Winkenwerder, Jr., MD (also represented by Carl Hendricks)

**Linda Springer,** Director of the Office of Personnel Management (during part of the meeting, Ms. Springer was represented by Dan Green, Deputy Associate Director, Center for Employee and Family Support Policy, Office of Personnel Management)

Douglas Henley, MD, Executive Vice President, American Academy of Family Physicians

**Jonathan Perlin, MD, PhD,** Under Secretary for Health, Department of Veterans Affairs and Veterans Health Administration

Michelle O'Neill, Acting Under Secretary for Technology, U.S. Department of Commerce

Kevin Hutchinson, CEO of SureScripts

**William Winkenwerder, Jr., MD,** Assistant Secretary of Defense for Health Affairs (Dr. Winkenwerder was represented by Carl Hendricks, CIO of the Military Health System, for part of the meeting)

Craig Barrett, PhD, Chairman of the Board, Intel

E. Mitchell (Mitch) Roob, Secretary of the Indiana Family and Social Services Administration

**Howard Isenstein,** Vice President, Public Affairs and Quality, Federation of American Hospitals (Mr. Isenstein represented Charles N. Kahn III, President of the Federation of American Hospitals—Mr. Kahn also was represented by Chantal Worzala, Senior Associate Director for Policy, Federation of American Hospitals, for part of the meeting)

Mark McClellan, MD, PhD, Administrator of the Centers for Medicare and Medicaid Services (Dr. McClellan was unable to attend part of the meeting and was represented by Tony Trenkle, Director of E-Health Standards and Services, Centers for Medicare and Medicaid Services)

**Gail McGrath,** President and National Director of Government Affairs, National Patient Advocate Foundation (Ms. McGrath represented Nancy Davenport-Ennis, founder of both the National Patient Advocate Foundation and the Patient Advocate Foundation, who was unable to attend)

**David Ayre,** Senior Vice President, Compensation and Benefits, Pepsico, Inc. (Mr. Ayre represented Steven Reinemund, CEO and Chairman of Pepsico, Inc.)

Scott Serota, President and CEO of the Blue Cross Blue Shield Association

**Julie Gerberding, MD,** Director of the Centers for Disease Control and Prevention, U.S. Department of Health and Human Services (Dr. Gerberding was represented by Ed Sondik, MD, Director of the National Center for Health Statistics, for part of the meeting)

**Mark Warshawsky**, **PhD**, Assistant Secretary for Economic Policy, U.S. Department of the Treasury (Dr. Warshawsky was represented by Adele Morris, Senior Economist, U.S. Department of the Treasury, for part of the meeting)

Lillee Gelinas, RN, MSN, Vice President of VHA, Inc.

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# PROCEEDINGS (8:30 am)

DR. DAVID BRAILER: Good morning everyone. I'm going to now call the fourth meeting of the American Health Information Community to order. Secretary Leavitt has been called to a meeting that could not be rescheduled. He will be joining us later this morning. In the meantime he's asked me to fill in as chair. He's also asked me to stick to the straight and narrow what we're trying to get done.

At the last meeting, we chartered four work groups and charged them with achieving certain consensus recommendations on the time period. Toward that end the work groups have held several meetings and have made measurable made progress towards fulfilling their charges. I've joined the deliberations of each work group and I have seen them organize themselves and are making great progress and are going to bring to the community today the early window into their deliberations, their assumptions and some of the early issues that they're shaping that will move towards recommendations. Organizing the number of people to each workgroup, the large distances, the time zones, the simultaneity of the efforts has been a significant undertaking.

I want to thank the workshop participants and the participants in the community who are co-chairs of that work groups for a monumental and important effort. I would like to thank the staff of my office and other federal agencies supporting these efforts because of their significance and intensity.

Before we move on to the work group presentations I would like to comment on three matters. First, the work groups have shown remarkable enthusiasm and creativity. I think we will see that very much today. And I know the discussions of the work groups have ranged across a wide variety of issues. This process is important and those deliberations are important. However, in considering the recommendations of the work groups, not just today, but importantly in the future the Community should remember that our charter limits our involvement in making recommendations about fiscal policies such as tax policies or reimbursement. Insofar as our discussions have touched on this I hope they will remain focused on the areas that are germane to the scope and cause of the American Health Information Community.

The second is an administrative matter, which is that the Community Meeting has been moved from the April 25th to May 16th and I think that has been noted on everyone's calendars and we'll make other appropriate public announcements, and I appreciate you all for accommodating that change.

And third, and most importantly, one of the people who has been central to ensuring that this process has been under way is Dana Hauser. Today is Dana's last day with us and I wanted to publicly thank Dana for her very, very hard work and outstanding efforts to help the American Health Information Community to become real and important and respected. I worked with Dana when she was the director of the Commission on Systemic Operability which as you know submitted its report last fall and in many ways that report sets the foundations for the work we're doing here. Her hard work has been appreciated and I assure you her absence will be felt. She is moving to take a Position at Novo Nordisk where she will be the Senior Director for their National Changing Diabetes Program. There's been much discussion about the staffing of the Office of the National Coordinator, I appreciate all the public interest in this topic. I think we should thank anyone who comes into public service on behalf of our health care consumers and Dana is one of those people. We're going to miss you very much, Dana, and wish you the very best.

### [applause]

With that I would like to turn to a quick update of where we are with our efforts and then we're going to continue with the scheduled topics of the Community's Meeting today. We were thinking about it is to help us understand where we are and where we're going. So we've to create a "You Are Here" map of our progress, and it is my hope that the staff of the national coordinator will continue to show this and help us understand this process and help educate those who are not sitting at this table about the complexities and the critical interdependencies of this process.

There are four major threads that are under way. First is the office of the National Coordinator Activities which we've talked about, with contracts and infrastructure and other work. Second are the infrastructures themselves the partners that are developing certification, developing architectures, privacy and security, the work of this community and then the new work we have now spawned of its work groups. And you can see that we have made remarkable progress.

We have now all four of these major threads of activity underway. And here we are today, which is March of 2006, we have a number of key efforts. We are going to start today in earnest developing recommendations that will come from this body ultimately to the department to other federal agencies and to other constituents in the private sector. We will within our office and within the federal government begin looking at these; in fact we've already begun discussing these.

So I want to remind us about our key goals here. The work groups are challenged with making recommendations around the four charge areas that we know, the Community with making its recommendations to the Secretary and I would comment that for us to have meaningful action within the department in this calendar year those recommendations need to be made at the May 16<sup>th</sup> meeting. So this is a very urgent timetable.

However the flip side of that is, after we make the first round of recommendations we'll be in a position tow begin our work groups focusing on the longer-term general charges they have, which has more time to play out, but the short-term effort to get the specific charge locked down is on an urgent basis. And of course, the office of the National Coordinator is continuing its efforts, not the least of which is development of a strategic plan that builds on the strategic framework that is -- was released last July and should be made available publicly at some point during this calendar year.

And of course those are all focusing on the ultimate goal of the interoperable electronic health record and other health information technology, tools, and services. So each of these has substantial complexity beneath them but we wanted to try to tie these together to help us understand, again, where we have come from and importantly, what the next few steps look like. So it is our hope not just graphically but from a process management perspective that we can begin moving this forward and having all of us understand where we're going. Are there any questions or comments here?

Okay, with that, I call your attention to tab 4 and before we do that, I'm going to ask for any comments on the minutes of the January 7<sup>th</sup> Meeting and in the absence of comments we will ask for a Motion that they be approved. All in favor?

And the minutes of the January 7th Meeting are approved.

With that we're going to turn to an interesting discussion that we wanted to begin windowing for you which is an effort we have underway which is the Gulf Coast Health Information Technology Task Force. And many of you know that this effort grew out of the efforts around Katrina health to be able to respond to the urgent needs in the gulf coast with the Health Information Communities special abilities as well as recognition that we have the capacity to contribute from a health information perspective to the rebuilding, not just of health information medical records but to the overall health care system in the Gulf Coast.

With that, we have three people with us today and I'm going to ask for each of them to introduce themselves so they can give you their backgrounds on why they are here to give you a snapshot of this effort and the task force that's being led by the Southern Governors Association and also our special efforts going on in Louisiana. With that I will turn it -- who's first? Lee? Lee Stevens will be first from the Southern Governors Association.

LEE STEVENS: Good morning. I'm Lee Stevens, I'm the federal policy director for the Southern Governors Association.

DR. ROXANE TOWNSEND: I'm Roxane Townsend, the Medical Director for Louisiana.

STEPHEN PALMER: I'm Stephen Palmer from the Texas Health Care Policy Council and the Texas Governor's Office.

LEE STEVENS: First of all we would like to thank Dr. Brailer and Health Information Community for inviting us here today. On behalf of the states of Alabama, Louisiana, Mississippi, and Texas, the Southern Governors Association is convening the Gulf Coast health Information Technology Task Force. The catastrophic hurricanes of 2005 revealed how vulnerable medical record data is in the United States today.

For the first time in US history medical professionals were faced with tens of thousands of evacuees who had little or no knowledge of existing medical conditions or treatment regimen. In many cases, their health history has been lost forever. Hurricanes Katrina and Rita revealed to Gulf State Governors the difference between localized emergencies and unprecedented regional catastrophes for which the health care system was unprepared.

Today, the governors seek to build the system to respond to a catastrophe and the mass evacuation of hundreds of thousands of people. Dr. Brailer approached the Southern Governors Association following the hurricanes and requested that we convene a task force among the four affected states to define principles and produce a roadmap in the region for and interoperable health information exchange network. Intended to be the first step toward rebuilding the medical records in the region, the Governors immediately recognized the opportunity to prepare the health care delivery system for a potential catastrophe in the future.

The task force we're putting together will consist of providers, payers, consumer advocates, IT professionals, business leaders and first responders who firsthand provided medical care to the victims of Hurricanes Katrina and Rita. Through the task force we intend to conduct return on investment studies and review of current state HIT efforts to inform Governors, task force appointees, and key decision makers of the value of establishing a regional information exchange network.

We plan to develop a set of goals and objectives initially to guide the work of task force and also develop a review of emerging national principles, standards and policies to guide state implementation. We're going to also define a set of principles that address organizational, legal, financial, technical, and clinical policies for the mobilization of health records to and look at an opportunity to leverage all the end-kind gifts that were offered during the days after Katrina and Rita.

Finally we are going to produce communications plan to encourage support for and adoption of an interoperable health information exchange network that the Governors will be able to use with their state legislatures and in the state community to guide the initial implementation. With that I will turn it over to Dr. Townsend.

DR. TOWNSEND: They say a picture is worth a thousand words so that is how I will share my message with you. Most of you recognize this if you've seen it on the national news. And that's a picture of the Superdome and the green building immediately below it is actually the arena where I had the opportunity to spend four days, three nights immediately following Hurricane Katrina. So I was there when the levee breached and the city flooded and I was there with the initial 12,000 people who were in the Superdome and the 20,000 who followed them. Many of them coming through the water.

I just want to sort of set the stage and let you know that I appreciate what you guys are doing in a very personal way because I saw firsthand what not having electronic information and the history of patients' medical records does to a patient and to the clinicians who are trying to take care of them. I was in the Superdome and I have recounted this story a few times but there was a 50-something diabetic woman who walked into the Superdome and she had followed instructions, she brought her Wal-Mart bag and it had all of her pills with her and she told me she was diabetic and by the way, these are the medicines I'm on. I don't know the name of them are, so when I took them out of the bag and saw the bottles the labels have been peeled off because of the floodwaters and what was left inside was a white slurry -- and that was what I knew about this lady's medical history, and that's not enough.

In addition to that, I saw nursing home residents had been delivered to the Superdome and the medical records consisted of a handwritten piece of paper that said their name, the ever important Medicaid number, perhaps an allergy and perhaps medications, and may be some problems. It was taped to the front of their gown. If it survived the transfer into the Superdome, it often did not survive any care they were able to receive during that time.

I have to tell you for me, this is really personal and really important, because if we don't do this for the safety and efficiency and all of those other things for our patients, then we really aren't about doing this, that is not the right way to be. What I wouldn't have given to have some -- a thumbnail or something about these folks that we could have offered something beyond "We'll do the best we can."

I want to thank Dr. Brailer in the early days after before I even got out of the Superdome, you and the Markel foundation and several other people had convened a meeting. There were 60 people, I think on the first conference call within two weeks after the storm. It's amazing; we had Katrinahealth.org and I can't tell you what that told me about the Health Information Community and what you can do when you gather around the right reasons and get the right people at the table. It was phenomenal. After that he actually offered Dr. Serise [spelled phonetically] our secretary of DHH in Louisiana, the opportunity to try do a prototype for health information exchange, and so we have a contract with Dr. Brailer's office so we are working actively be actually be able to have some of that interoperability and recover and recreate a lot of these Katrina evacuees medical records, and I thank you for that.

So thank you for letting me be here and I thank the Southern Governors Association for the work they're doing, because they have a unique perspective to be able to bring heads of states together and actually talk about reproducing what we can do on a local level and make it interstate I think is wonderful. Thank you.

STEPHEN PALMER: Dr. Brailer and members of the Health Information Community. Thank you very much for giving me the opportunity to speak to you today. I'm here representing the Texas Health Care Policy Council which is a new entity in the office of the Texas Governor. Established through legislation, signed into law by Gov. Perry in 2005.

One of the charges given to the Texas Health Care Policy Council is to coordinate and facilitate all the mission technology initiatives throughout the state. Texas was among the states affected by Hurricanes Katrina and Rita and we saw firsthand the consequences of paper based health information system. Although the recent hurricanes drove home the importance of health information technology, we in Texas had already started down that path with Health IT initiatives

at both the state and regional levels, including the creation of the Health IT advisory committee, to develop a long-range IT plan for Texas, the establishment of the several regional health information exchange projects, both urban and rural, the promotion of electronic health records and other clinical informatics, by professional associations within the Texas healthcare industry, and a recent series of health IT forums throughout the state to engage regional stakeholders, at which I presented Gov. Perry's vision for health IT in Texas.

The health care policy council in the office of the governor will seek to coordinate and align these various health IT initiatives. We will also be working closely with the Texas Health IT Advisory Committee to serve as a health IT resource and for state policy makers and develop options for legislative consideration. In addition, we will be participating with the Southern Governors Association, on the Gulf Coast Health IT Task Force, charting a digital recovery for the health Information infrastructure of the gulf coast region. Within this context I will be serving as the governor's primary liaison on health IT issues.

The reason that the Texas Health Care policy council has taken such an active role in the promotion and coronation of health IT Initiatives throughout the state is because Gov. Perry strongly supports health IT and is a firm believer in its potential to improve the quality of health care and contain health care costs while protecting the privacy of personal health information, supporting biosurveillance activities, and improving emergency preparedness. Thank you again for inviting us to be here today. We look forward to working on Gulf Coast Health IT Task Forces for the Southern Governors Association and the American Health information Community.

DR. BRAILER: Let me thank all three of you for coming and for your very hard work on behalf of all of us in the Gulf Coast. I would comment to the community that among other duties, the Southern Governors Association task force will be making recommendations that we will bring here about health IT crisis response recommendations; things that we can do to supplement the work in my office and that I know in some of the federal agencies about responding to the next disaster, God forbid it comes.

With that, we have a few minutes for questions and discussion but this was intended to be an early glimpse at where this is heading and it is our expectation that as this task force and the efforts in the states progress that we will continue to report here with more substantive matters. So are there any questions or comments that the panelists can respond to? Kevin.

KEVIN HUTCHINSON: Just curious in going through Katrinahealth.org and the creation of katrinahealth.org. What are the most important elements you found during the disasters that you needed at your fingertips if you were to prioritize the top three to five different data elements that you really needed during that time?

DR. TOWNSEND: I think actually, with Katrinahealth, they really capture, certainly, probably the low hanging fruit, the things that were easiest to get and that was the medications which are also really the most important. By looking at the patient's medication history you really can sort of recreate, you know that they're diabetic or if they're on blood pressure medicine they have some sort of cardiovascular issue. So I really think that.

The piece we did not always have in there consistently, and it's a harder piece to capture, is allergy information which would be very very helpful. And then The other piece we would love to have if we're talking about just the basics is a brief problem list so anything that perhaps is not being medicated is under control, you would know about those things.

DR. BRAILER: Doug?

DR. DOUGLAS HENLEY: Dr. Townsend, I think about three or four weeks ago there was a program in New Orleans that I know several physicians, special societies, Intel and others were involved in in providing personal health records to thousands of folks in New Orleans. Can you tell us how that went and how does that connect with the program that the three of you spoke to today?

DR. TOWNSEND: The New Orleans' Health Department sponsored that event along with many other people. It was a Health fair that was actually done at the Audubon Zoo and they actually were able to create some personal minimal health level information for several thousand citizens down there and they were able to give each of them a flash drive that had their information on it. And it was very successful, and they have information in a database and have permission to use that database at least for those individuals -- in case you need to recover their information.

It is our hope that long term we will figure out how to share that information because as we develop our health information exchange one of the things we do want to create is a continuity of care records that would include many of the data elements that they have collected in New Orleans.

DR. BRAILER: Lillee?

LILLEE GELINAS: Thank you so much for being here. I am from New Orleans and so I personally saw through the faces of the 26 members of my family that we took care of after Katrina and know firsthand what the loss of records and prescription histories are. When you're considering and you may not know this answer now, but maybe it's a question you're going to be considering -- I think about my 83 year-old mother who probably as of five years ago did not know what a computer was, couldn't use a computer. Just thinking about the adoption issue of those who can't use computers, the elderly -- talk about the nursing home patients who you took care of. So there is a segment of the population that we have to be ever cognizant of as we move towards an electronic system, how are we going to deal with their issues and their needs.

I don't know if you have had a chance to talk about that yet but it seems like a very poignant issue when we make recommendations we're certainly going to have to address it. My 18 year-old son is in the Nintendo generation, and he loves all of this so his adoption won't be an issue at all.

DR. TOWNSEND: Exactly and it's certainly something I know HHS has been having to deal with. You know, my mom is 76 and when I told her she could get prescription drug information on the Internet she looked at me like "Yeah right." So it is going to be an issue but the initial adopters really need to be the provider sector and it's going to be our responsibility as providers to make that information available to other providers. And then down the road if you're talking about a personal health record and being able to access that, certainly an issue we need to address and I can tell you, we haven't thought that far ahead. I'm sure other thinkers are way ahead of us.

DR. BRAILER: Mitch?

DR. MITCH ROOB: Have you had -- at the risk of sounding like a former budget director, have you had and opportunity to tangibalize the financial cost savings that would have accrued had you done this? So if you had lived through this experience, this would not have fixed the levees but it would have fixed what happened after the levees. So what was -- if you had it, how much money would you have saved, how many lives would you have saved? I mean can you tangibalize what that cost, what the return on this investment is?

DR. TOWNSEND: Specific to Katrina I really can't tell you because unfortunately one of the things that we don't know because we don't capture it electronically right now is how many errors were made in people's care based on not having the information at hand. We don't necessarily know that but certainly if you look at a lot of the studies and the return on investment, things that has been looked at for health information technology, the estimate is somewhere around 30% you may save by saving redundancy. Some labs have actually reported that when systems went electronic, the orders for labs went down 30% and so it depends on whose side you're on, on whether that's a savings to you or not.

### [laughter]

DR. ROOB: I am familiar with those studies. I think the issue here from your perspective is you can prove the worth of this financially. I think that may be helpful to tangibalize the financial cost of not having the system. Because ultimately it will be about the allocation of scarce resources.

DR. TOWNSEND: One of the things I actually had just asked one of my programmers this morning, I want to get some idea of the redundancy of tests we saw ordered post Katrina. And that may give us a glimpse for some of the ancillary testing that we did. The medications, most of those were lost, we ended up paying for those to be filled again anyway and I don't think any -- none of the IT stuff might have made a difference in that. But certainly some of the ancillary testing -- that's something -- I actually just shot an e-mail this morning so maybe I will have some information for you next time.

DR. BRAILER: Any final comments or thoughts? Thank you. And to this comment that Mitch raised, we will follow up with SGA about making sure that some evaluation can be at least considered in the work that we're doing. I would also say that we've worked very closely with the Markel Foundation on an after-action evaluation of KatrinaHealth and the other health IT responses, and those should be made public soon, so that will give us all more to debate about how do we make sure that the Health Information Community is part of the solution in the future. Thank you all very much. We look forward to seeing you again at some future meeting. We appreciate you coming out.

With that, let me turn you to Tab 5, and we now will conduct the first deeply substantive review of the four specific charges that we've made to work groups. As you all know, each work is chaired by two members of the Community and have a large number of very talented people who have supplemented the work of the Community in these work groups. We've reserved a significant amount of time -- an hour or so -- for each work group recommendation, that is to allow a small amount of time for a presentation of the actual report from the work group, and the remainder, the majority of the time, for this group to discuss.

So with that, let me turn to Craig Barrett and Mark McClellan for the Chronic Care Work Group Report.

CRAIG BARRETT: Thank you, David. Mark and I will try to do a tag team on this as we go through the presentation. The first couple of pages, I think, are perfunctory in terms of just the work group membership, and also the work group charges.

I might just make a brief comment on the work group charges. We've had discussion within our work group about the exact wording. Our interpretation is effectively that we need to facilitate secure communications between clinicians patients and caregivers, and the secure transmission of information and data, and if you read the words in the broad charge or the specific charge, I think you can see that there are perhaps slightly different interpretations where it says communications between clinicians about patients. We're interested in communications between clinicians, patients, and third party care givers, and that would be in fact -- think of members of the extended family of the patient who may be a local person interacting with the patient and interacting with the clinicians.

The next page is in fact talking about the enablers to accomplish this specific charge and focusing on the specific charge of the work group and not the broad charge initially. From an overall perspective, let me just comment that our interpretation of the importance of this particular subcommittee is that we've heard testimony and evidence that some 80% or so of the cost of the health care system is associated with the aged or chronically ill people, and therefore if you don't do something to address the cost associated with this small population of the total citizenry of the United States, you're not going to address the overall cost of the situation.

A 50% improvement of the other 80% of the healthy population would probably accomplish less than one year's inflationary adjustment for the overall health care increases, so from a simple Predo [spelled phonetically] analysis, either you do something with the chronically ill or you don't touch the overall cost of the system.

Very simply, then our discussion of enablers focuses on the short term low hanging fruit, using existing infrastructure, existing systems, existing secure communications, dealing with clinicians who are -- have a high percentage of patients who are chronically ill, and looking at how we could build off of existing capability to demonstrate the cost-effectiveness of this situation

So as you go through and read the five enablers on page CC4, you'll see that it focuses to a great degree on existing capability and trying to leverage that existing capability going forward. I might turn it over now to Mark and let him talk a little bit about what CMS has been doing in this space and his interpretation. Mark?

DR. MARK MCCLELLAN: Thanks, Craig, and we have been spending a lot of time thinking about these issues. Obviously, Craig talked about the 80-20 rule for the general health care population, with Medicare it's even more extreme. Over 90% of the spending in the Medicare program today goes to the treatments and complications for chronic diseases. That's changing in Medicare as we're bringing in more preventive benefits and prescription drug coverage to get more of an orientation toward prevention and pre-emption, but at this point that's where the vast majority of our health care costs are going, and we have a lot of enablers who can help us make some real progress on using secure messaging to help deliver more effective and better coordinated chronic care.

We've spent a good deal of time hearing from clinicians and not just physicians, but also nurses and also associated health professionals that are often very much involved in the ongoing care for patients with chronic diseases, and that have a lot of excellent ideas as to how the care for patients with chronic diseases could be improved.

In the Medicare program, again, we see very high costs associated with potentially preventable complications of diseases like heart failure, diabetes, chronic long disease, other very common conditions. There are a number of enablers that can help add to just the need to deal with this burden of disease, just about all clinicians who care for Medicare and Medicaid patients have a substantial burden related to chronic disease. If it's not the bulk of their patients, it's certainly the bulk of these clinical time, and the bulk of their billing.

One of the challenges we have is that in many ways, our payment systems don't support the delivery of well-coordinated prevention-oriented-care for chronically ill beneficiaries, so I can't tell you how many times I've heard from physician groups, individual physicians and nurses who are caring for some of our patients with diabetes who have really good ideas for how they could use electronic medical records or even the telephone or other basic technologies to do a better job of intervening early, educating patients about their illnesses, keeping track of tests that have been done at other sites, or gathering information from patients from home, who say, look, we'd like to do this, but under the payment systems you have now, if we take these steps to improve coordination of care and prevent complications, we get paid less.

You've got a fee for service payment system that pays more when patients have more visits to the doctor, more complications, more potentially duplicative procedures, and it's true that largely our payment systems today in the traditional Medicare program are based on the delivery of specific services rather than the quality of the service or its impact on patient health. And so we have been working with a number of physician groups, individual physicians, and care management, disease management organizations to change that.

We'll talk a little bit more about that when we get to next steps. But with these kinds of payment reforms, what we're increasingly seeing is the adoption of systems including messaging transfers to help manage patients with chronic diseases more effectively and at a lower cost. So there is a lot of potential here, including the use of secure messaging to get to better results, at a lower cost in our health care system if we provide the right kind of financial and other supports for it.

CRAIG BARRETT: Our group had a lot of discussion on the topics that we've mentioned, including such mundane things as, does in fact a electronic record of communication between patient and clinician enhance or deter the possibility of litigation following the treatment, and it seems to be a split in the discussion, or a split in the ideas on that particular topic.

Another topic that has come up frequently in our discussions has been the issue of from a clinician side that this is a wonderful idea as long as there's a standard template in terms of the communication protocol. No one wants an eight page summary from a patient and all possible communication styles and prose about what's wrong but they want a standard template so that they can assess the communication and act on it in a short period of time and not have to read page after page of prose associated with the patient.

So, lots of work going on in this space today, and there's lots of systems: VA system, Kaiser Permanente, many systems and Mark has mentioned they're in communications with, are already having trials and various systems going on. The bottom line though, is perhaps the last sentence on page CC4, which is the enabler here is in fact reimbursement associated with less costly care effectively that provides better care than bringing the patient into the office or the emergency room.

And so it's not just reimbursement for an electronic message, it's reimbursement for improvement in the cost-effectiveness and quality of the care, and I think this will be obviously one of the challenges, and it's been a challenge already, associated with the system.

DR. MCCLELLAN: You could just tee-up the discussion of recommendations to support these enablers, there clearly are a lot of opportunities through the visibility and collaboration of the Office of National Coordinator to move and add some real momentum to the process of using secure messaging and purchasers payers and consumer groups, opportunities for us to collaborate with other health plans and other care delivery settings.

Just for example, in Medicare we've had reforms in recent years that have brought a lot more Medicare advantage health Plans, coordinated care health plans into the program around the country. And not just in urban areas anymore, but now large regional plans that are operating across broad multi-state communities as preferred provider organizations. In these plans we're paying not based on specific services but based on the health status of the patients who select certain plans.

So if you want to take advantage of the new financial support and Medicare for health plans, the only way you can do it is attract and retain beneficiaries with chronic illnesses, and beneficiaries with chronic illnesses -- or their caregivers or family members -- have a pretty good idea about the care that they want to get and it's not poorly coordinated, duplicative care. We are seeing a lot of these health plans, Craig mentioned Kaiser, that's certainly some of the PPOs are starting to use secure messaging and other types of electronic support for their beneficiaries with chronic diseases. Now in the Medicare Fee-for-service program, it's a little bit more challenging because their payments are not based on care coordination. There, as Craig said, we have been moving towards paying more for better results for patients and lower costs.

Just to give you a few examples quickly, Medicare started in Medicare Health Support program last year that pays organizations an additional benefit and Fee-for-service Medicare for providing care management and disease management services to beneficiaries with heart failure, diabetes, and other common costly chronic diseases. These organizations don't get paid for delivering more services, they get paid for better outcomes and better clinical quality of care, better patient satisfaction, and lower overall cost of care. And these programs are frequently using electronic health information, supplemental information on their beneficiaries. They're using some of the same kinds of personal health records that Roxanne and others mentioned earlier and in some cases, they are using secure messaging as well. And we think that with the support of this group we can use this program to promote the use of secure messaging even more widely.

We have also started a program on care management for high-cost beneficiaries. As Craig said, this is where the money is. This program is testing some provider based intensive care management services as a way to improve chronic care management for our beneficiaries who have a high expectation of complications and very high Medicare costs. This enables us again to pay for better results, lower overall cost of care when participants primary and specialty providers have better ideas on how to deliver services and this is the traditional Medicare Fee-for-service approach.

This pilot program is going in seven states, six programs and it is frequently using a health IT with secure data communications among providers, lots of use of telemonitoring for distant patients so they can be monitored in the home, problems can be identified early and transmitted back to physicians and nurses involved in this program and they can take steps to head off complications and avoid not only the hospital or emergency room visits, but even the visits to the doctor's office.

One program called the Health Buddy program is operating now in Oregon and Washington incorporates a device that coaches beneficiaries of about their health, and remotely collects information on vital signs, symptoms, transmits those results back securely to the health care providers that are involved in their care. All of this is happening now because we are paying more for better quality and lower overall cost of care rather than the old system, where if a group of providers had wanted to use remote monitoring techniques like this to keep track of how their chronically ill patients were doing would end up getting less billing form Medicare and it just wouldn't make financial sense.

There are many opportunities to build on the steps to say we have seen strong interest as well through groups like the Ambulatory Care Quality Alliance in identifying and providing better financial support for steps like secure messaging that can lead to better quality and lower overall cost of care as well.

CRIAG BARRETT: I think what you're hearing from this subgroup is in fact the key issues are: use the existing infrastructure to find some good examples, quantify the bottom line results and pay for quality or pay for the bottom line result, not just pay for another service, the other service being the security email communication. We really want to see some bottom-line result come out of this.

I should also mention as you see at the bottom of this page 5 there is also a minor issue of transcending state boundaries and state licensure requirements, especially in rural areas where in fact the physician may be in eastern Montana or the patient may be in western South Dakota, but the ability of a doctor to transcend state boundaries, we think is probably critical to full implementation especially in the rural areas.

DR. MCCLELLAN: That's an area where Medicare kind of has an advantage because we have some broad authority to preempt some of the usual rules that limit how a plan can function across state lines. And from our experience it certainly can make a difference to especially improve care for rural beneficiaries and those in more remote areas.

CRAIG BARRETT: The open issues if you go to page 6, perhaps the key one here is how best to evaluate the effectiveness which is the key issue in terms of providing reimbursement for this new service. Secondly, what infrastructures and programs could be best leveraged and where, and David this is an area, I think that we both rely on your office and also the work that CMS has been doing. There is the issue of how you define what sort of messages would be considered reimbursable and this is again back to the evaluation of effectiveness. You want to reimburse something that provides results, not just reimburse a new communication channel.

Then also the standard issue of workflow issues in the office or another way to look at that is how can you, in fact, have a standard template for the patient and the clinician to communicate within a simple straightforward format such that the doctor doesn't spend half of his time answering E-mail like those of us in the business world where we have no standard formats for our communication channels.

### [inaudible]

Half of the work day and half of the work night, I think is our standard. There is an opportunity here at the outset to create some standard communication protocols to ease the burden on both sides. There is some obviously work going on in this area already, and we ought to make use of the best known methods. Mark, if you have anything to add on this page.

DR. MCCLELLAN: Our next steps are effectively to look for receptive environments in areas which are already utilizing this technique and build off those best known methods. Again, focusing on results to support the reimbursement policies that come forward, to relate results to the new technology and that we'll continue to reiterate the importance of that. This has to be results oriented approach and not just another service oriented approach. Then to look for other issues as to whether it is a licensure issues or federal entities, organizations that can assist in this area.

As we're doing a [unintelligible] analysis the 80-20 rule in terms of 20% of the patients consuming 80% of the cost of the system. When we get within that 80% of the cost we also ought to look for the 80% of that cost associated with even a smaller patient population to drive the program to show the quickest results so I would assume that we have an 80-20 and then another 80-20 segmentation after that for the demonstration framework.

DR. BRAILER: Okay. Thank you, let me thank your work group for obviously a significant amount of work since our last meeting. And as we turn this to discussion of the Community, which we have ample time for at this point, I want to make sure you're focusing your thoughts and comments on understanding and probing what has been put before you with an eye towards helping this work group come back to us at the next meeting in May with very specific recommendations that are actionable by this Community so they can be transmitted to the Federal government, to other agencies, to private sector entities.

With that, let me open the floor and I will turn it first to Bill and then John.

DR. WILLIAM WINKENWERDER, JR.: That was a great presentation, I was both interested in reminiscing on Mark's comments about the importance of the payment system to achieving outcomes and like many others here having gone through the managed care and prepayment and capitation initiatives, some of which are still around from the early '90s and largely the failure of that, unfortunately from my perspective in terms of promoting responsibility on the part of the providers to manage the care and take the steps that would lead ultimately to some financial reward for them.

At the same time achieving a good clinical outcome for the patient or population of patients. But I am curious, to ask Scott, what your sense representing a large number of private plans because ultimately even within the Medicare program you're turning to private plans to implement these Medicare Advantage products and concepts. I am interested, what is your sense about the prospects for re-emergence of payment mechanisms that move away from fee-for-service and more to group payment and prepayment?

DR. MCCLELLAN: Well, we have some pilots that are under way, primarily Blue Shield of California that has an excellent program that they're looking at trying to incorporate this. The more generic question about a move back to capitation, while it has some appeal intellectually, I just don't think the marketplace, particularly in provider market is ready to be in a risk assumption business.

The greatest difficulty we ever had in capitation was with chronically ill patients anyway. This would not be the first place I would start trying to reintroduce capitation. I think I am very supportive of the goal of developing reimbursable mechanisms of communication so long as that caveat that Craig put in this that it was improving the outcomes, the question is how you measure that and how do you measure that in advance. The communications will take place long before the outcomes will be known so how will we know when we are paying what the outcome was good or bad or whether we're just in the scenario of filling time if you will, paying for more and more communications, increasing the cost of care and not having a positive outcome on patient care.

I think we have to do some more work about how we tie these things together. I think the ultimate result is some kind of packaged reimbursement for service. It may not be the pure capitation model that we used before but it may be a disease specific payment, it may be some kind of more global payment like the surgery payments that at least in the old days used to include pre and post care and all of those of the things, some kinds of payment mechanisms more along those lines to try to incorporate and [unintelligible] these kinds of tools. But my discussions with providers across the country would say a move back to capitation and risk assumption by the providers is not high on their list of objectives.

DR. BRAILER: John Perlin.

DR. JONATHAN PERLIN: Thanks. Let me echo in congratulating Mark and Craig on an excellent presentation, really bringing up one of the central challenges in Health care and the Southern Governors Association presentation really highlighted what happens in the absence of information around the chronically ill patients.

All that being said, I think what was so impressive to me about the work group's deliberations were that -- which you brought forward, the issues were not technical. It wasn't invent a technology that does not exist it was really not the hardware of the software, it was the [unintelligible] it was the alignment of incentives, the behavior of individuals to create a more functional relationship around the three players, three actors that you identify: the formal clinicians, patients and the lay care givers as the individuals.

I would just acknowledge there are some technical implications that dovetail with probably all of the groups in terms of authentication, authorization in terms of the assurances that the players are who they represent themselves to be and that one can assure that. But I'm going to put that aside for a moment. It really comes back to I think what the question is: with a vision that you present that's so compelling, it's really an extension of Bill's comment. What are the mechanisms to line the incentives to create value proposition for this to gain traction? I would just open that for others for their thoughts.

FEMALE SPEAKER: Craig, Mark, could you talk more about secure messaging and what your group is doing on that and what kind of, we were looking at really?

CRAIG BARRETT: Probably the bottom line response to that question was anything other than standard E-mail. Any let's call the secondary system which is a private security system that runs off of the standard internet E-mail approach and there are lots of examples of this already in existence between patients and care givers and lots of examples in the financial industry and our own industry for example. What we quickly concluded was you just don't want to have a standard e-mail form of communication so you want to be able to have the patient to go into let's say effectively a closed environment within the health-care system, obviously password protected and identification protected but not a standard open e-mail system or patient just emails doctor and vice versa.

DR. MCCLELLAN: We've seen a another number of different versions of what Craig said some of our programs when it's an actual health plan involved it has at least some at electronic record capability. There will be obviously some security features built in there and messages related to the patient's chronic conditions status and updates being included in this in those limited electronic or personal health records. We've seen as some providers as part of these programs using secure e-mail to exchange information among each other to improve the coordination of care for chronically ill beneficiaries.

I was having a conversation with David Brailer recently about the use of web-based portals for transmitting information securely. One of the programs, a program run by Humana called Green Ribbon Health has this secure messaging via portal built in they're starting to use and we're really in the phase of gathering information about how well it's working. In some ways it's a little more work for the providers involved because they have to get on the internet and log on securely to the system and then get their messages in but it does open up the possibility for a lot of different participants in this process of care coordination to share information effectively. I think there are a lot of different possibilities at this point and as Craig said, the main thing we have been focusing on now is making sure they are secure and evaluating which ones seem to work best in which circumstances.

DAVID BRAILER: Doug Henley.

DR. HENLEY: Great discussion and great work in the work group. Apropos the Community, it seems that I agree that the focus now secure messaging from one clinician to another to patients to care givers is a critical first step in all of this. Again, let us not forget at the end of the day if we can get the whole system electronic with full medical records, everywhere, that will fully allow all of this process to occur in a seamless fashion and will allow each clinician and the patient and the consumer to deal with issues of accountability and cost and quality etc... But the enabler of payment as it relates to the provider of the service as everybody here has said it will be critical. I would agree with Scott that certainly the physician community I doubt would want to go back to the days of pure capitation.

There had been over the course of the last -- since the demise of prepayment, if you will, in the mid to late nineties there have been a series of excellent reports, Bob Barrinson [spelled phonetically] has published some good work in Health Affairs. There was The Future of Family Medicine Report two years ago, the recent report by ACP about the impending collapse of primary care, just a whole myriad, Barbara [unintelligible], etc... that shows, and I think reveals the potential for a blended payment system that would include fee-for-service properly modified by some degree of pay for performance that we are already talking about privately and publicly and perhaps the concept of the care management fee which will capture some of these additional services in a preprepayment fashion in addition to capitation augmented by pay for performance. I hope that we can move in that direction.

I know, Mark, the 721 pilots through MMA are looking at just those types of potential options. We don't have the results yet but we soon probably will have preliminary data from those results in six or nine months. And hopefully that will reveal improved cost efficiency, improved quality with a different methodology of how we pay for those services that will incentivize improved quality.

DR. MCCLELLAN: Let me just add to Doug's comments, AAFP, also the American College of Physicans and many other physician groups have some excellent ideas about how this kind of blended payment system could move forward. Many physicians aren't ready to take on full capitated risk for especially their most chronically ill high-risk patients, but the proposals the physician groups have developed would allow for our reimbursement systems in Medicare or health plans to provide better support for the kind of care coordination in a more manageable risk environment. That's where these kind of blended payment systems come in. So we looking for all the opportunities we can find to get these ideas into practice and get them tested to see what kind of impact they can have.

In some of the settings where we have applied these AFP types of ideas so far, Doug mentioned section 721, we have seen more investments in electronic health records and broad care coordination support technologies that go beyond just secure messaging and to the broader ability of health information systems that support more effective care coordination and lower-cost of care. We're hoping to do more of that in the very near future with small physician groups as well. I think these same kinds of principles that AFP and others have developed can apply there too. So there's a lot of promise in the very near future for the kinds of ideas that Doug's talking about.

CRAIG BARRETT: David, getting back to your admonition about sticking to the purpose of the community. I think the messages is, as you well know, that you can't separate the advancement of technology from the issues of payment, but the payment issue becomes enabling to adopt the technology and to implement the technology which is what we are about here in the Community.

DR. BRAILER: Thank you. I think that's recognized. I appreciate it. Kevin Hutchinson.

KEVIN HUTCHINSON: This is really a question for Mark. You made the comment about some of the programs that you're deployed or looking at from the CMS standpoint, that some physicians are using IT frequently, using IT solutions. Those that aren't using IT, how they report on quality indicators or improvement of care without IT?

DR. MCCLELLAN: Very good question and one that we're spending a lot of time working on with physician groups like AFP and the AMA. There are approaches based on claims data reporting that physicians can use now. So we started, for example, a voluntary reporting pilot program where for a set of validated clinical quality measures, physicians are essentially adding additional code reporting into the current billing systems in Medicare.

There are different ideas for doing this, and I think the one that has the most momentum right now is to expand the so-called CPT level two codes and AMA has been working with us in a broad collaborative group to get these kinds of codes in place for valid quality measures related to chronic conditions like heart disease, diabetes, and diabetes results, and so forth. So you would report on whether or not a patient had a hemoglobin A1C level in the optimal range, for example.

As we get these systems implemented, which I think is essential and very short term for the physicians that don't have full electronic capabilities, we're paying a lot of attention to making sure that we can also support the electronic reporting of this kind of information.

In one of these demonstration programs that we're implementing this year, for example, we're paying more for reporting using electronic information systems that provide them information as incentive to adopt the information system but also to use as Craig was suggesting earlier, to make sure we're getting better results for what we're paying.

So I think we're in a phase where we need to support both the claims based reporting on quality measures as well as the transition to a broader use of electronic reporting because so many physicians don't have electronic records fully in place yet. We need to view this as a transitional period where both types of reporting are supported.

KEVIN HUTCHINSON: Just as a follow up on that. Have we looked at the increased revenue versus the expense to the physician with respect to these programs, and is there a time estimate of how long we are or [unintelligible]...

DR. MCCLELLAN: That's exactly the right kind of question for these evaluations. How do you design these blended payment systems to have an appropriate balance between limiting risk that providers phase so they're comfortable with the payment system but also providing the new directions in the financial support so we can really enable physicians better to deliver more effective care at a lower cost. They don't have payments -- it's awfully hard to make your bottom line practice financial management work.

DR. BRAILER: Howard and then David.

HOWARD ISENSTEIN: I just want to go back to what Doug was talking about in terms of payment or reimbursement and incentives. We have kind of a good and a bad model at the same time with hospital compare where there is process measures and now coming on board outcomes measures and we could, for example, weight the outcome more importantly than the process, the process being you use an electronic messaging, etc... and you get a score there and then maybe another score for an outcome mortality, for example. But the issue there is that's only the stick. If you don't report it you get hit with a cut, versus getting paid more for adopting it. I would say that would be important to consider.

The second thing would be if you have it on a hospital compare or transparent reporting system with private payers, that would really help the consumer to realize in a fast way that this is important for my quality of care. Exposing it to them and having them broach the conversation with the physician or the hospital about, "Well, why do I have to fill this form out four times? I understand electronic messaging will help my outcomes." So try to get it as part of the dialogue and that will encourage the provider to adopt.

DR. BRAILER: David.

DAVID AYRE: I may have this all wrong, I may not be understanding the conversation but let me see if I am and then throw a suggestion from a consumer standpoint. What I think I am hearing is that this is a great thing but if we can't figure out how can we incent people how figure out how to use it, it's not going to go anywhere. So technology isn't the barrier, and privacy is a concern, but how do you get there. And the people paying the bills, if I'm hearing it, are the employers or someone saying how can I know that I'm incenting and getting a good outcome, is that sort of what I'm hearing?

Because here's my question: if I'm a consumer and the only of alternative to getting care is to get out of my house or wherever I am and travel somewhere and do things, my time is worth a lot of money, and everybody's time and there are costs that aren't reimbursed in the medical system that are inherently -- your time, your driving there, your effort, so maybe the consumer would just be willing to pay if there was a dialogue between their provider and them about this and if we're going to dialogue and do this way, here's the cost, and then let that be the incentive.

Is that just either -- perhaps it's wrong or a completely stupid idea I'm not sure, but to me, I would pay a lot of money to not have to go a lot of places to very quickly get some kind of service that I am ultimately the judge of whether I'm getting better as a result of it.

DR. BRAILER: David has asked a good question about how the consumer ultimately gets what they want from the machinations of the health care system as we go through these things. Let me ask anyone that would like to comment on that idea particularly with an eye towards guidance to the work group as it goes offline after this meeting.

DAVID AYRE: People use the ATM because they didn't want tellers [unintelligible]. Now you go to the ATM because it's more convenient and you pay a fee. And you love paying the fee because it just gives you the money. So that's what I'm getting at.

CRAIG BARRETT: To a degree, online shopping is the same issue. I pay the service shipping charge for the convenience of not having to go to the store. I very willingly do that. Frankly, I would be very willing not to go to my doctor's office and pay some degree of fee as well. I think we can integrate that into the whole compensation system.

MARK MCCLELLAN: I think that's absolutely right and it highlights why it's important to give consumers an opportunity to save money when they get their health care. Building in reasonable ways to do that is I think what a lot of these reform efforts are about. For some of the beneficiaries in our program, Medicare and Medicaid, there is only so much we would want to do with out of pocket financial incentives. We have got to get people enough financial support to get the care they need.

For many people in the health-care system and for people with limited means, a health account or other types of consumer driven care approaches that give people an opportunity to save while still giving them adequate financial support to give them the care they need is a great way, I think, to encourage the use of these kinds of services.

In many of the long-term care services we pay for, for example, we work with states and their Medicaid programs to give people with disability more control over how the funds for their long-term services are spent on their behalf, and many people choose, when they have that option, to get out of an institution with a very expensive setting of care, and live in the community and make investments in modifying their home to provide technology that can keep them in touch with their care giver, that can make it easier for them to get around. It is win-win. It is cheaper overall in delivering care and it gives people more control over getting the kind of care they want and living the life they want in the community.

So I think there are a lot of opportunities to do this that recognize that consumers can be terrifically powerful forces for more effective delivery of health care especially for chronic diseases where they are very familiar with their conditions and what it is they want if they're given the right opportunities to do so.

CRAIG BARRETT: One thing, David, that we should not lose sight of in this discussion is back to the 80-20 rule. You're either going to impact the cost of health care delivery to that 15 or 20 percent of the population in a material way or you don't accomplish anything. Anything that would diffuse the efforts back to the broader population and make it more complex to introduce I think we ought to put in second-tier. We ought to focus very strongly on the small number of people who are eating up the bulk of the health-care cost. That is the chronically ill, and just focus on that part of the population. Even though it might be appetizing to look at this population around the table and say we're all healthy people and we hate to go to the doctor's so can't we have something -- I'd rather focus our energy on the chronically ill portion of the population.

DAVID AYRE: I'm thinking those chronically ill people, If I'm following your point are likewise consumers who are willing to value their whole life and time in a certain way, they may be willing to contribute.

CRAIG BARRETT: No doubt, I just want to keep emphasizing this 80-20 rule as we go forward though.

DR. BRAILER: Just continuing on this thread and then we'll continue with the other dialogue. If I'm the consumer whether I was paying for it out of pocket or because my health plan or for another reason is there what a way I could find physicians or providers who were willing to engage in that communication process with me? Is there a directory or a set of questions to ask to be able to find providers that are so equipped?

DR. MCCLELLAN: Going back to Howard's comments earlier there is some information that consumers can use now to help find where they can get the best care for their needs at the lowest cost and the tools that go along with that. Some of these elements of quality or process measures whether or not a certain drug is used or an electronic record is in place, things like that, increasingly we are trying to make information on outcomes and costs available. That is a critical part of a transparent and effective health care system where people can make effective Decisions and avoid unnecessary costs in the system.

I think there needs to be a lot more support for consumers along those lines and it should include process measures like whether or not best medical practices are being followed, whether or not electronic records and the like are being used but also outcomes. What you're likely to end up paying for your care and what kind of results you're going to get.

DR. BRAILER: Mark.

DR. MARK WARSHAWKSY: To continue this conversation I use that analogy which we used at the beginning many times, the application of the information technology which leads both to a better outcome and lower-cost to those who pay for the services, I fully recognize the reimbursement issues and the incentive issues involved with payments to providers but I want to be sure that the group does not lose sight of -- in a very tangible way what the ultimate goal here which is to -- one of the ultimate goals which is to not only get better quality but also to lower costs for the ultimate payers for these services which has been the great experience of the application of information technology.

I'm very -- a little concerned about -- some of what I've heard that those savings would be captured which would not be an outcome that I don't think anyone would want to see. It really is a question to the work group -- beyond quality measurement, is there any way of structuring this is such that we're sure of the cost savings that could arise from this could be captured ultimately by the payers?

DR. MCLELLAN: I think, Mark, in terms of competitive approaches there are a number of health plans Or a number of disease management groups that are available and competing for the beneficiaries to take advantage of the services that are going to tend to drive down the cost of delivering services. People choose providers that save them the most money as well as get them the best help but that again goes back to David's point about making sure that consumers have opportunities and the information they need to find the best care, the best coordination of care at the lowest cost.

And some of the programs that I was talking about earlier, we are basically sharing some of the savings that arise, so in the Medicare Health Support Program, for example, the organizations that are providing disease and care management services are paid essentially entirely on a contingency basis, so to have payment, or what you might call rent, they've got to improve quality of care, improve satisfaction, and lower the overall cost of care for the beneficiary and the program, and Medicare shares those savings with the organization, so there are some, you would say, rent involved, or some benefits to the organization when it delivers better quality and lower cost, but they're only arising in the context of getting reduced Medicare costs for taxpayers.

DR. BRAILER: Doug and then Dan.

DR. HENLEY: I want to go back to David's question because I think it's a good one. Even if we turn the switch right now and we had this secure messaging across the system, but the work group report did not address is barriers to implementation even if the technology was there to allow it to happen. I think there is a big barrier that we have that relates to the relationships between the patient and the provider apropos David's question of who is paying for this electronic secure messaging.

Should it be the consumer, the patient, should it be the third-party payer if insurance is involved, what ever the case may be. The point is, it's not clear and we need to make it very clear. Is this new relationship, this new service we're identifying that is occurring by secure electronic messaging, it is a covered service for those who have insurance, even if they have an HSA if they spent their \$1,000 deductible at some point in time, their insurance is going to kick and so is it a covered service or a non covered service and therefore it is in fact a financial relationship between the provider and the patient directly versus a third-party payer. We have got to make that very, very clear as to what the service is and who is responsible for paying. Is it covered via the insurance model or is it a direct financial exchange between the provider and the patient?

DR. BRAILER: Dan and then Lillee.

DANIEL GREEN: Thank you. Just kind of covering a lot of what has been talked about here at the table, I know within our program within the federal employees health benefits program, for a number of years we have been, I've especially been frustrated -- we've shelled out money, we think, for disease management programs and seen very little in the way of a cost-benefit analysis or quality improvements in hard raw data. This is beginning to change, however, as some of the better programs are merging with their chronic care management systems, their regular care management programs and as those two come together, they're seeing some cost savings.

My suggestion, to get back to the immediate charge of this work group is that focus on the implementation of these messaging systems within the existing chronic care disease management, care management programs that already exist, that already have a payment structure in place that have some measures for quality, payment issues are already there. Don't have to deal with the broad structure of paying individual providers and how that works. I'd suggest using that as your starting point and working out the methodology and the technology and then that can be spread to other sources.

DR. BRAILER: Lillee.

LILLEE GELINAS: David, I wanted to get back to your comment about personal incentives and to the work group, just looking at the specific charge that would have to be accomplished by the end of the year and the communication between clinicians and patients, did the work group comment at all about patient incentives?

David, I think you made a good recommendation around but he would be willing to pay for in this day and age but in many ways we can't legislate accountability. And you know, if I am overweight and I have chronic conditions no matter what happens I don't go on a diet, who is accountable for that and we keep paying? It really piqued my interest, David, when you made the comment about personal incentives and the notion of personal accountability because it seems what I'm hearing from the work groups so far is still having a provider centric system. Is that an accurate assessment?

You know, we talk about secure messaging -- we're still talking about a provider centric system, not a patient centric system and some of the breakthroughs we talked about in our first two meetings were around the personal aspect, e-health, a patient being specifically accountable. So I just wonder if you had any pithy discussion around the issue you hear at the other end of the pendulum, you know, and I guess up a very poor example would be if you're in a car wreck and you weren't wearing your seat belt and your insurance wouldn't pay.

I don't know how those, where the personal incentives come into play because I know how hard it as a nurse in front of a patient and try to coach a patient around, Please you have [unintelligible] stop smoking. Or please lose some weight, or your diabetes is going to get substantially worse, and we're going to have to amputate your feet if you keep this up. So when we talk about a chronic care group and payment did the work group talk about that at all? Because when David said that it really spiked my interest. Are there personal incentives that we could really put into place to make this work?

CRAIG BARRETT: I think the simple answer is no. We have not had any pithy discussions on that topic. The focus was rather, there are existing programs, existing infrastructure. There is a firm belief that secure electronic communication either advice of the type you're talking about or data transfer back-and-forth, or information transfer back-and-forth has to make the system better and has make care better. Should we spend our energy trying to demonstrate that and demonstrate it from an outcomes basis as opposed to kind of a detailed carrot and stick approach in either direction. We haven't had those discussions at this stage.

DR. MCCLELLAN: I think can build in more discussion about patient responsibility and patient opportunities for savings as part of the program. David did make the point that there are opportunities for people to save money or get more convenience in the care they deliver and that is one reason that we really would like to see more opportunities for patient decisions, patient control and patient savings as a result of those decisions in our programs.

I'm sure that there are a lot of secure messages that consumers, properly informed, would find worthwhile. I suppose there are a lot that they wouldn't want to bother paying for just like there are a lot of MRIs or other lab tests and procedures that we pay for now that consumers were paying for on their own, they probably wouldn't find worthwhile. I think we can try to build that into the further work of this group.

DR. BRAILER: Ed Sondik then John Perlin.

ED SONDIK: The model that I hear you talking about, the image I have is of ambulatory patients at home. Have you thought about, for example, patients in nursing homes and how certainly a great percentage of those are chronically ill, some with actually acute illnesses for that matter. I was thinking maybe and I'm not sure if this fits the 80-20 rule but one of the issues that always for patients in nursing homes is the communication with the family. I wonder if this could be an application that one might be willing to -- a family might be willing to pay for.

DR. MCCLELLAN: This is absolutely a part of the programs we are implementing now. Sorry if I gave the wrong impression. Maybe of the best opportunities for preventing chronic complications are in frail older patients who have high risk of costly complications ranging from medication interaction problems to nutritional imbalances to pressure ulcers.

In Medicare we have a number of programs now as we have moved our payment systems to pay more when you care for a patient with a high level of chronic disease and frailty, and nursing home levels of care, we're paying a lot more for plans that take care of those patients now and we're now seeing a number of plans in Medicare that specialize in this kind of care delivery that are using electronic records, messaging, other kinds of steps to do early monitoring of these patients, to stay in communication with their caregivers or family members so they can head off these medication problems or bedsore problems and the like. I think there are a lot of opportunities there already and you're absolutely right that that is where we ought to be focusing on a lot of effort.

DR. BRAILER: John.

DR. PERLIN: Sort of a first principal question, I don't know whether it is assumed but VA is where rolling out structured communication we do a lot of remote physiological monitoring, part of the value is that it supported by a totally implemented electronic health record and so regardless of where the patient is and which provider answers the message, the information is available 100% of the time.

My question to, briefly, Craig and Mark: it would seem that there is value both in the structured communication as a good in and of itself but that would seem that there is even a synergistic value with the point of this group, the advancement of the electronic health record in supporting the structured communication with that sort of information, and so is this seen as a good? Is it seen as a catalyst for advancing the electronic health record? Is it seen as something that builds on or some combination of the three?

CRAIG BARRETT: I think it is seen as very synergistic. Obviously, the environment we see enabling all of this was described as a strong environment recognizing the strength and capability of Health IT to drive this forward and that is basically chronic health records, that is why we propose that the demonstration proofs, if you will, should be those areas where electronic health records and health IT are held in high esteem because this is an integral part in demonstrating this.

Sometimes I think when we have our discussions we tend to immediately jump from the VA Type infrastructure to the individual practitioner and assume that there is a continuous capability between the two and there is in fact, not obviously, and we thought that the best area to go after were, in fact, those institutions or capabilities with a strong investment in health IT, a strong capability in health IT you can demonstrate the outcome very quickly.

It is very similar to the discussion we're having last night in the VA system. If you have can do remote monitoring and you have an electronic health record, and any clinician can have access to that this is a very efficient system. It does everything from prompt the patient if their weight is going up or their blood pressure is going up or blood glucose level is drifting, to do something about it. But without that infrastructure, without that environment you're starting from scratch and I'd hate to start from scratch in the system.

So our discussion base was let's go to where the action is today and then use that capability to demonstrate the outcome. The outcome has to be lower cost and this is the Industry Rep in this environment I will keep telling you, 16 or 17% of GDP, is in fact a boat anchor around the economy's neck. And if it gets to 25 percent of GDP, I can tell you where the jobs are going to go. You have to recognize that and so the ultimate has to be holding the cost essentially where there are while delivering better care. I don't know how you do that without the infrastructure you're talking about. Our whole focus is to leverage off existing interest infrastructure capabilities that demonstrate the results and then to use that as the leap frog to get other people to do it, not to start from scratch.

DR. MCCLELLAN: To reinforce Craig's point perhaps not so colorfully, the kind of payment systems where you are paying more for better quality or lower costs, the kind of steps that encourage consumers to get more actively involved in getting better care at a lower cost and saving money in doing so, that can reinforce effective secure messaging but it also is going to reinforce all of the other features that you have right now, Jonathan in your electronic records and personal health records systems. It is all part of movement towards getting lower costs and a more competitive economy.

DR. PERLIN: Your comments are extremely helpful and I agree and fully endorse that strategy. I think it leverages very quickly. I hope next meeting will be about to share an article we didn't set up to be as an experiment, we use real time observational data but we can associate with the implementation of health record at is 32% increase in efficiency, so I think it is pretty remarkable, measurably better outcomes, quality, and satisfaction with the same resources for patients as a decade ago in nominal dollars with 350% more sites of access so I think if I had to bet on a technology to rationalize and improve efficiency and outcomes this is the [unintelligible] and I think your proposal to leverage those sites that have invested in that to complete that next link of rationalizing, is the good bet.

DR. BRAILER: John, we'll work with you to share that with the work groups before the next meeting. Good. Let me turn to Gail.

GAIL MCGRATH: I have a comment and question. The comment is that as we have as a society moved into the age of specialization, while consumers I think would like to have one provider in charge of their health care, that's just not the reality. The reality is that consumers typically are going from specialist to specialist and we just don't see that many family practitioners anymore.

To me, that is what as consumers, that's what makes it more important that consumers have input on their care, that they had the ability to access information on their care and particularly with my generation, not necessarily with my mother's generation, with my generation, we are eager to have the information and we see that from consumers every day and they want to be part and parcel of this partnership of their health care as Mark was talking about. So that's just a comment.

I do have a question. On the cost, is the cost with the chronically ill or is it with the terminally ill in that 18 months of life, is that, how do those measure up?

DR. MCCLELLAN: There is obviously a lot of overlap. Many of the people who are chronically ill many who do have conditions that are often fatal. We don't have perfect predictors ahead of time about all of those cases but whether or not we do there are tremendous opportunities for care coordination improvement and care toward the end of life as well. Better pain management and better coordination of medications, more timely responses to the new patient needs, family needs and development so at the same kinds of tools that we are talking about and talking about for the chronically ill I think applies to end of life care as well.

DR. BRAILER: Mitch and then Kevin and I think that's our last comments.

DR. ROOB: Thank you. Gail, if I could respond to your question with some tangible dollar figures. We currently have about 9,000 developmentally disabled adults in Indiana living outside of institutions at an average price of \$40,000 a year. That does not include the medical care or their prescription drug costs which is substantially greater that, so add another \$10,000 for that.

We have 26,000 senior citizens primarily, and some developmentally disabled, living in nursing homes, again, about \$40,000 per person without what we call planned cost which would be the Medicare benefits that Mark sees that never hit my budget. It is an extraordinary expense for a patient population that isn't necessarily in the last 18 months of their lives, these are folks who are going to be there for, in the case of the developmentally disabled, the rest of their lives. In the case of the nursing home residents, 4, 5 and 6 years.

As we move to a de-institutionalized setting, that care coordination and the use of electronic record to do that is critical to try to maintain the cost structure as exists and I think that Dr. Barrett's point about focusing on those extremely expensive folks, I would just amplify to say it is probably 90-10 other than 80-20. It certainly is in our sense. It's 90-10.

As we move to a de-institutionalized setting, making sure we can get that information, the technology exists to get the information into home and community-based places where home and community-based care is actually delivered. The infrastructure we need to be aware of that as well and make sure that a layering exists, particularly in rural areas.

DR. BRAILER: Kevin do you have a final comment?

KEVIN HUTCHINSON: I like where the conversation was going. We have a lot of conversation about the financial incentives that are needed to try to drive the adoption, and we kind of moved toward processes because that was going to be one of my comments. I think, as a work group focused on chronic care improvement one of the things we need to look at is the data elements that are needed both on the providers' side as well as the patient's side to really drive an incentive for them to use it.

For example, we can do the online visit which is great and probably a good focus area, but if a patient could request a refill electronically, if they could schedule an appointment with their physician, there are other elements other than financial incentives that improve the processes that will itself drive adoption by both providers and physicians, and a physician's ability to reply to A refill authorization request either approve or decline and have that go. There's efficiency savings there.

Ultimately as we look at chronic care improvement, one element we have not touched on today is around the medication adherence and compliance, which these tools could actually help track, especially for the chronically ill, the ability to make sure patients are actually taking their medications and taking them as prescribed. My comment is more focused on making sure we look at the processes as well as the data elements including the financial incentives that would drive the adoption in this space.

DR. BRAILER: Okay, thank you. This discussion evidences the kind of result that we wanted when we chartered the American Health Information Community, a deep and substantive look at a particular topic as a lens on how we have been improving health care. I want to emphasize that as the work groups return to their efforts after this meeting we have to have our eye on the May meeting with these recommendations have to come forward.

This discussion is very helpful in framing that, but as the work groups go off and deliberate and discuss, it is our expectation that they will be able to come back with very specific recommendations now that will help this group decide if it will pass those forward to the department, other agencies in the federal government, to other entities in the private sector. The work group can do this with their own deliberations but we also encourage that they get public testimony or ask for letters or other inputs to make sure they're representing a broad needs and expectations of those in the health-care sector.

So with that we will take a break and resume at 10:15 with our consumer empowerment work group. Thank you all very much.

[begin 2<sup>nd</sup> session]

DR. BRAILER: We will now resume with the consumer empowerment work group and I'll ask the members of the community to turn your notebooks to tab 6 and we'll turn it to Linda Springer and Gail McGrath, who I think must be still out. I guess we're still on break then. It's a general rule if the co-chair is not here to present it, we will continue our break.

LINDA SPRINGER: The other co-chair appreciates that.

[low audio]

DR.BRAILER: Let's go ahead and start. I think Gail may have been detained. With that I'll introduce Linda Springer, the Director of the Office of Personnel Management who will start this initiative and we will turn again to tab 6. Linda?

LINDA SPRINGER: Okay, good, thank you. I want to just say that my co-chair in this, Nancy Davenport-Ennis who is not here today, has been very active and been a good partner in helping us to get do this point. We have a very good representation of what I believe is the right community and the community of interest for this work group and for this portion of the overall effort. Nancy today is represented by Gail McGrath who is here at the front table and I also want to thank Dan Green who frequently represents me here and in our work.

So everyone is doing a terrific job here and we have had very active communication. All of our meetings -- all of our meetings of the work group have gone at least for the full amount of time and to keep that type of a group participating and alert for 4-5 hours straight is an accomplishment. I think that shows the level of interest we've got.

So moving right into the slides, I want to just tee this up by saying that we can have the best construct in the world. We can have the best technology in the world, we can have all the other things that are part and parcel of the effort here, but at the end of the day, the end user, the consumer has got to be comfortable with whatever it is that we build and whatever we -- whatever is introduced and made available and that comfort level is going to be critical to having a successful outcome.

The consumer in our minds, is looking in two dimensions and I think that's captured in our charge. If you look at that, you'll see in the broad charge, words like, gaining widespread adoption, obviously a personal health record that's easy to use, portable, longitudinal, affordable, and consumer-centered. And you could even take consumer centered by itself and that would capture the rest of it.

But that broad charge, I think, starts to get at in a very high level way the fact that it's got to be accepted. It's got to be easy to use. It's got to be -- it's got to have the right balance between level of information but privacy and all the other things that go with that. When you get more specifically into the charge, the specific charge we have been under, you will see there the idea of making the recommendations, obviously, so that within a year a pre-populated consumer directed and secure, again, similar types of words, electronic registration summary is available to targeted populations and you'll see one of our efforts has been around, what are those target populations?

Make additional recommendation so within one year a widely available pre-populated medication history -- so a related outcome in medication history, linked to the registration summary is deployed. So those are our charges. And then the presentation that follows relates to our work in moving towards fulfilling those charges.

So we can go to the next slide which is the principles. We believe that before we went too far, we needed to develop a set of guiding principles. These are principles that are primarily focused on the consumer perspective with respect to the ultimate outcome tool and here is what they are, and by the way we are still reviewing these. We are going to continue to fine-tune them. These are ones that we believe and that the work group and the groups that they represent believe are important things that as this is being developed, as it's being constructed, that everyone bears these types of guiding principles in mind.

So I'm going to pick out certain words and highlight them. You can read them as well as I can.

There's some important things here: that individuals have the right to access their own health information. This isn't just something out there that they never are able to see what is in there for themselves. It should be convenient and affordable. They should be able to access it but without it being so burdensome or cumbersome or certainly affordability is a factor. So that's another aspect of our principles.

Individuals should know how the information is going to be used and who is going to have access to it. That's a real key one. And there's some secondary ones that derived from that about control. If they don't -- if they feel this is out of their control, they don't have any type of say or control over how this information is shared, to how their health record is shared, how their medication information is shared, if it's totally out of their hands and don't understand it, how it's going to be used, that's going to be problematic.

Protections, obviously protections over the integrity, security, privacy, confidentiality, all of those are a part of what we need to ensure for the consumer to make sure this is a successful product. And then the overall governance and administration structure that surrounds how this will be used, not just how it's built or how it's constructed or rolled out, but the ongoing use. We think it's important that there is transparency and public accountability.

So those are guiding principles we have, again, with respect to not just our work but we think these are ones that have applicability in all aspects of the work that we are doing here.

I think we're going to take questions about these things at the end so we'll just go through the presentation if that's okay because I think there is a logical sequence in the slide. So we'll keep going if that's okay.

All right. Now, with all those principles in mind, and guiding our work and I hope as I say, ultimately guiding everyone's work here, we started to say, well, what are some of the policy issues? What are some of the challenges we will have as we develop some models for, and develop some of the target populations where we think we have got the highest degree of receptivity as we consider a roll out?

Now some of the things that we're considering as far as issues with respect to a roll out are on this next slide. There are issues around raising awareness. There's an educational process and we've got some communities that are very knowledgeable. We had a -- OPM had a workforce conference for the civilian workforce last week in Baltimore and one of our speakers was Secretary Nicholson from the VA and he could give a very vivid testimony, candidly to people who have benefited from the VA system, of their having the medical records and prescription history in the VA system.

There was the example that he gave of someone whose baggage and whose information was lost in flight when he was coming back into the country. And he got right in touch with the VA and by the time he arrived at the nearest VA hospital, someone met him at the door with his insulin medicine, the right level of insulin. He was diabetic and the information was there within the system and not only did he -- it wasn't that he had to wait or see somebody or fill out forms or get information and then eventually got it. Someone met him at the door as he arrived with his medication. So that was a very vivid information; we believe that those types of examples and education will form the basis of a good education and help raise consumer awareness of PHRs and the whole medical record opportunity.

Confidentiality. We need to deal with confidentiality. I said that before as a principle but it's also an issue from a policy standpoint. There will obviously be some policy issues that we will need to support making sure that we have dealt appropriately with confidentiality.

We believe there may be a need for patient proxy. Liability of providers. Have to look at both sides. Not just the consumer side but the provider side. The risks and how do we mitigate those risks?

State laws. There are all kinds of state laws, a variety of things. Part of my background is in the insurance world, life insurance and there were always issues around privacy and around what's the right use of information you get about someone's health and about their medical history. And insurers are regulated at the state level, so there might be state laws. That's just one example we need to take a look at and make sure there is nothing that will come up at some point in the process that we haven't considered.

Data standards. Very important. Not just data that is -- that will fit into an IT structure and I don't mean to minimize that. But it's quality of data, not just how the data is expressed. Data standards and getting consistent data standards. Lack of interoperability. When we're sharing information, we could say all these in a positive sense. I think a lot are put up in the cautionary sort of expression but we could also flip them around and say very positively we have to make sure that things are interoperable and that's true of all the things here.

So this is a list again. I think you'll find in all our slides we have lists that are active lists. They are living lists if you will, in a sense we will be adding to them, refining them, in many cases simplifying them, and obviously we are interested in any input and comments of things as the other work groups tackle their respective issues that should be addressed.

And again, our focus is the consumer and so even some of these have a broader impact, our focus is with respect to the consumer, how do these issues come to bear?

There are breakthrough models, potential breakthroughs we are considering. We presented three on this next slide that we think should be considered. I'm sure there are others but these are three that the work group has put down for your awareness.

Use of existing regional health information exchange with the consumer interface. Second, PHR vendors linked to one or more intermediaries to get updated information. Another model, a third model that we've presented here, would be payer or employer based portals that could supply information to PHRs. We are exploring those, we're exploring others. And again, for those models that are already out there in one form or another, we'll be looking to those to see what we can learn and what might be applicable to our effort.

Now in the next slide you'll see potential target populations. And the main criteria that we've presented here is that these are population that is include people and we used the term patients, but they are individuals who have frequent use, would have frequent use of the system. One thing there would be people of chronic conditions or people who are either in an age group, young or old, who have maybe a more frequent usage.

So that would include the first two, the pediatric population and then the second one we identified here is the older -- now above 45 isn't old to me. I don't know about you, above 85 maybe. But at

some point, you start to get into a greater usage, particularly with respect to prescription drugs and certainly we see that in the federal government's health plan that prescription drugs and usage of that at the higher ages is a major part of the activity they we see. So above some age in the population there is a more frequent usage of the prescription drug part.

And then there may be other local or regional or geographical consideration that is would present or lead to a population that might be a good target and I'm sure there are others. Obviously there are geographic areas that have higher risks and where there might be more of a higher use profile. So we'll be looking to explore and even better articulate what some of those would be. Again, in all these cases, we are happy to have input and thoughts from other members of the community here.

Now one of the things that we are looking to do and we've started with, and many of the people in our work group are already or have already done this in another context, is to continue to get an inventory of the existing models and characteristics of different models. What are the data? What are the elements that are included in these models and there are ones out there. I mentioned the VA. There are other models that are there and so from our very first meeting we indicated, we decided that it would be helpful for us to get started on some sort of inventory of information about the various models that are out there and while we don't have a slide on that, that is another thing we are doing.

It follows the principle that we have that we don't want to reinvent the wheel. If there are things already out there, we don't have to start from a blank sheet of paper. At the end of the day what our recommendations will be will be informed by those other activities and other trailblazers, if you will and other products that are already working and working satisfactorily and very effectively in many cases like the one that I gave the example of earlier. So we're not trying to reinvent the wheel. We're not trying to start with a blank sheet of paper, but at the same time we are not just accepting what others are doing without putting it to the same tests that we would any original idea and again part of that test is relates from the beginning with those principles and then goes forward.

We do have some open issues here that are on the last slide or next to the last slide. Again with respect to policies, with respect to various guarantees, various assurances that we need to give to the consumer group that there is just relevant data. That there are mechanisms in place, safeguards. Safeguards might be policy, safeguards might be actual securities or mechanisms within the construct of the PHR, the HER, to make sure that whether it's some sort of protection, actually an access to data. So safeguards take a variety of forms.

Again the liabilities, the clarifications on what should be included. What shouldn't be included and we also believe standardization will be very important. You could easily have people move from one system to another system, and standardization could play an important role.

So those are things that are part of our agenda as we meet in our succeeding meetings. We'll be streamlining as I said. As you look at the next slide, refining, streamlining, dealing with open issues and again, testing out other breakthrough models, target populations, and we'll come back with those recommendations and we believe that -- we still continue to believe this is all doable but I just want to reiterate that on behalf of the work group we really, really believe, no matter how good of a product we build at the end of the day, consumer acceptance will be the key to its really achieving the goal that we are all after.

DR. BRAILER: Thank you, Linda before we continue, I'll just ask Gail to make other related comments.

GAIL MCGRATH: Thank you. When we first started this process, Secretary Leavitt directed us as members of the Community to reach out to as many groups as many people as we possibly could to get input and certainly from the consumer prospective, that was very important. And we certainly took that to heart. We have been working with what we call our internal group, which has to do with about 30-40 different consumer groups. We also have been working with the Markel Foundation who has a group of about 45 different consumer groups, companies that they actually have been working for the last two to three years on guiding principles on if, when the health IT goes through, how do you make sure that the consumer is part of the process? What means the most for the consumer? And I believe all of you have been given the letter that the Markel Foundation -- is that correct? David?

DR. BRAILER: I think so.

GAIL MCGRATH: But I'd like to read just a part of it, not the whole letter. The -- certainly it was to bless the process if you will. But also to say that the health information technology agenda will be slowed and put at risk unless the AHIC establishes a public process to develop and disseminate policies to guide the work of federal agencies and contractors and provide voluntary guidance to health information exchange efforts in the private sector.

I think that our thought process and certainly I think I can speak for the Markel Foundation here, is that IT in isolation just will not work. That as Linda said, if the end user and it will either the provider or the consumer, but the end user has to buy in. So, the guiding principles that are put forth here and certainly from not only our internal working group, but also the Markel Foundation, are the same as you see in your slide, but, to keep in mind that just as IT is developed over time, so should the principles because IT changes over time so then the principles should also.

So while this is a very good starting point and we would like to see certainly even if it's a little policy group formed but something that will pay attention for this, so that the contractors for all of the working group get this information and understand what's important to consumers.

DR. BRAILER: Okay. Thanks, Gail. Let me thank the work group for a substantial effort. This is something that also of us watched the tremendous efforts put in by the chairs and the participants and with that, let's open the discussion again with an eye towards giving guidance to the work groups so it can produce recommendations that advance this topic during the May meeting

[low audio]

DAVID AYRE: First of all, we should clarify. I'll go by Dave and you go by David.

DR. BRAILER: Okay.

DAVID AYRE: Commenting on the last comment --

DR. BRAILER: I was trying to understand what I actually said.

DAVID AYRE: They are agreeing so that will make that my comment. So just to -- the concept of principles I found over time are a great way to start anything and I think any group that thinks about that I've found because principles stand the test of time, right. Things change and principles do that, and I've also found that if you don't like the principles you can change them later and create other principles, so that's a flexible terminology. So I think that was great.

When I looked at the principles the one thing I would suggest maybe is that there is a lot of things about what the individuals should have. There may be something that you may want to consider about what the accountability of the individual should be. Like the concept of that consumers need to be accountable for their own health record and updating it. It's not everything we should be giving them, as maybe what we expect from them or what the Community would expect from them.

LINDA SPRINGER: That's a good point.

DAVID AYRE: And the other thing is, Bill and Craig's point, I really like this concept of --and just from PepsiCo's perspective. We have 6% of our population gives me 50% of my hundreds of million dollars of costs. So I think this concept of targeting populations, like pediatrics is a very good idea. And I think that where health care will go is eventually a changed behavior and building the behaviors in from Day 1 of an individual's life where they are used to technology and their immunization records and everything that's happened is going to be the long-term solutions in this country by -- right now kids pick up computers and cell phones just like TV controls for me and what I think what you want to do is just build this in. Because eventually having electronic health record will be like a birthright and this is what people will do and they're just going to assume this is how it works. So starting the parent and the pediatric off that way and transferring it over that way is maybe too long for us but is a good idea.

GAIL MCGRATH: Actually you saw that in our targeted populations that the pediatric group might be a good place to target because you do have a starting point that will lead over time. So we did think about that.

DAVID AYRE: It's a great place to start.

DR. BRAILER: Doug?

DR. HENLEY: Well, excellent work by the work group. And I thank Linda and Nancy and Gail for that presentation. Under the slide CE8 where you got have listed the open issues, and I emphasized this at previous meetings of the Community. I just want to say it again. I may sound like a broken record but it's going to be critical to maintain interoperability between personal health records and EHRs.

We've got a certification process in place for electronic health records. It's my understanding, I know Mark Leavitt is in the middle part of the room. I believe, Mark, you said at your presentation last time that later this year, the commission may be addressing the PHR issue to some extent but personal health records must interoperate with certified EHRs. The certification process should accept those standards by which PHRs can plug and play. So the vendors for PHRs in some fashion should be required, should be encouraged, should be whatever, to pay attention to the EHR certification process so that they have to plug and play with the rest of the system. That's just going to have to happen. If we miss that opportunity, we miss a huge opportunity in terms of the

portability of data from one part of the system to the other and the accuracy of the data would be at risk.

GAIL MCGRATH: We totally agree with that, Doug, and I think the emphasis is again on the end users, the consumers, providers, you have to have buy in from everybody. It just will not work without that. And so it does then have to be interoperable.

DR. BRAILER: I would also comment for those of you that don't watch the arcania of our budget process, that in the president's FY07 budget request, for health information technology that there is a line item for personal health records. And as that goes through the process, and comes out as an appropriation, we intend to use that to support exactly that effort of ensuring that there are standards and that there are linkages between personal health records and the rest of the health information infrastructure. Bill?

DR. WINKENWERDER, JR.: I'm about to do something very dangerous. Wonder allowed in a public forum. But I just can't resist it. And I'm thinking and looking at John. We have both have electronic health records systems, and the way you have teed this up, you have spoken in terms of the need potentially for a portal with just registration information, medication history, allergies, that is something we collect in both of our systems.

We also interface with -- on the DOD side -- about 230,000 physicians in our network so that it is an extensive reach. It's not all physicians. About a third of the doctors in the country between our populations we have about 30 -- you have 20 million eligibles and we've have 9. So almost 30 million. Not all are users but it's a large -- and I'm wondering -- with the dangerous wonder aloud, if whether we ought to think about and I'm looking at our CIOs and people who have to figure out how to do this, but to create a portal that had that basic information as a starting point to...

DR. BRAILER: We'll put DOD down for 30 million.

[laughter]

DR. WINKENWERDER, JR.: No, it has to be technically feasible. We're only a partner. We're half of a marriage with the VA but I don't know, John.

DR. BRAILER: Let's turn to John, but I think this is the spirit of innovation we are looking for.

DR. PERLIN: Well, in fact, when we first and very much endorsed Doug's comments about the interoperability because of our envisionment of where personal health records are going we want it very much to be a window on the patient's record -- not our record -- the patient's record and make it useable and valuable to them. But we are changing our mind-set. We always looked at our population of those patients come to us but when we developed [unintelligible] actually we took more of a public health approach and it is available on-line to individuals who might want to enter their own data and develop a basic step.

Now in terms of the vision you present, we don't interface with the other entities that would populate that information automatically which would really accelerate the value even further but in fact it was that inoperability with the underlying health records that allowed Linda to recapitulate the Secretary's story.

Some people said me how did you learn about the situation? Truth be known, we got a note from the patient's mother. But it's really that linkage that allowed that to occur with the health record. But the other is I think we do have not only an opportunity but a responsibility for a more public health approach.

DR. WINKENWERDER, JR.: So, I -- let us take it off line.

DR. BRAILER: Could you take that back to the work group?

DR. WINKENWERDER, JR.: I think we should take it to the work group. We are working towards interoperability of our systems and moving information and already doing that in a significant way, but what strikes me with this is it's a sub set of all the data that we already have that then might be more easily available to our covered populations as well as to a broader community of medical care providers. Who our population goes to and sees from time to time when they are not using us. So, anyways it might be a way to pull people into --

DR. BRAILER: I think so very much and so let's transfer that to the work group and have your staff follow-up and begin looking at this.

DR. WINKENWERDER, JR.: Okay.

DR. BRAILER: Chantal?

CHANTAL WORZALA: Along those same lines, there are a growing number of providers who are giving views on to their medical records, I'm thinking about my charge, Cleveland Clinic, some of the innovators out there. If we can get to the point of really having the specifics of what are the data elements, I think it may be possible to look to providers also when you are thinking about what are the different models out there? Can we ask those providers that already have EMRs to again pull out that sub set of data? And make it go faster that way, because again they already have it.

I also wanted to say I liked the principles. I thought they were very solid and it is true you definitely need buy in from all sectors before you can really move forward and but a little bit of a caution on the notion of patient control. I want to make sure that we are not going outside of the bounds of what HIPAA has already put in place in terms of access to records and ability for providers to share in information for clinical care, for health care operations. So just want to make sure we are not going beyond those bounds as we talk about patient control.

DR. BRAILER: Kevin.

KEVIN HUTCHINSON: I just want to, as a member of the work group, I wanted to bring up some thought processes we had with regard to the portal. We kind of followed a path that said it should be patient's choice of entry into this personal health record world and we think a portal is a great idea. We think that you could actually accelerate the use of it. That portal could either come from your physician's office, it could come from your payer, it could come from a number of different sources.

Or kind of in the analogy of the electronic banking world, follow the path as some do banking on their bank's website, some use Quicken or Microsoft money to do their banking as well as their investment banking, they have one view into all of their records versus in the banking world where you're using an on-line portal you might only have that bank and go to a different portal for your investment banks. We followed the conclusion that the best approach underlying architecture should be about patient choice, however we do think there needs to be a way, just like there is in the banking world to update information which in turn would update it in a variety of areas.

We tried to stay away from the idea of a master database of this information but in effect what we are trying to do is get rid of the clipboard. That was the mission that Secretary Leavitt put us on for this particular workgroup and what is on that clipboard, standardized the information on that clipboard but then if a patient chooses to use a client server software tool, how do we then integrate that information to allow it to be updated between those two and then shared with the physician's EHR system from interoperable standpoint.

We also do agree it needs to be pre-populated to have it manually entered information would probably take a long time before we'd find any use out of that.

One comment I'd like to make to the group is one of the major issues I think we're going to have in this area is the various state laws that exist out there around privacy. And there is a debate in the industry -- we really didn't get into debate in this topic in the work group, but around the view of sensitive medications, as an example. Whereas we all know, the anti-psychotics and the behavioral and AIDS medications and things like that are some of the most dangerous drugs to have an intersection with yet in many states that's information that can't be viewed and so there's an argument in the industry that we have to address is, is partial information more damaging than being able to view the entire record of information?

Obviously we always have to have the information validated with the patient. That's always the provider's responsibility to do that but it's an issue we have to address in the industry as to whether or not we're going to be able to just as we do all those medications, keep them private and stay away from the separation of the medications.

DR. BRAILER: Michelle and then Craig.

MICHELLE O'NEILL: Thank you very much. I think looking over the principles you've clearly articulated the patient's rights, if you will, to protecting their personally identifiable information with regard to access, use, collection, security.

I'm wondering and it could be embedded in these, but in order to build trust, I think being able to clearly articulate and intelligibly communicate to the consumer is important and I don't know if the work group considered that, but I think that should be a part of going forward. It's good if they have these rights but being able to communicate those rights to the patient I think will build that trust.

LINDA SPRINGER: I think that's a very good point and probably language does need to put that because I think that one of the problems we see now is that consumers really just don't know what their rights are and certainly when they go to a provider, they don't understand what they can ask for or what kind of information they can get or -- and even if they ask and can't get it, they don't know where to go then, so I think you're right, Michelle, it probably should be added.

MALE SPEAKER: I would echo that. Principles are important and the foundation, but those principles have to be translated into practical, operational inscription information instructions. And an explanation.

DR. BRAILER: That is what the work group will take up at the next meeting. How to translate these principles into the specific recommendations and actionable items and I think clearly there's has been a lot of dialogue about that so this will feed into that very much. Craig.

CRAIG BARRETT: Just had a question. We had a presentation of the post Katrina situation with the Southern Governors. We had a health fair recently in New Orleans where I believe some 18,000 people registered for a PHR. I'm wondering if what went on in New Orleans was consistent with the principles?

LINDA SPRINGER: What I think went on in New Orleans was what went on in New Orleans. I can't answer your question on that. I do believe, though, for a certain group of the people there that had they had some sort of card with their own information I think they could always carry with them and I think it would have been a little bit better.

CRAIG BARRETT: I'm talking specifically with the 18,000 people that were registered and walked away with what they believe is a PHR. If that was consistent with your working group's definition of principles. I'm asking because I don't know.

LINDA SPRINGER: I think David will have to speak to that because I wasn't involved in that so I don't know.

DR. BRAILER: You're talking about the health fair?

CRAIG BARRETT: Yes.

DR. BRAILER: Well, my understanding of the health fair, and you probably know better than I, is that was a tool that a consumer could put their own health information into as opposed to something that was pre-populated. So it raises the question about the principles, about control of health information and about how health information flowing through the health care system is managed by the consumers as opposed to their own outlet for it. So I guess my high level view is it's not inconsistent but it's not a direct manifestation of these principles either.

CRAIG BARRETT: I was -- I guess I was interested in whether it was inconsistent with, not consistent with. I mean it was basically a one day, pre-population of the -- of patients health record to the best of their information plus also a preliminary doctor's exam. Looking at the principals and it seemed to me it was consistent with and not inconsistent and I was wondering if anyone had looked at that in detail.

DR. BRAILER: We haven't. Ed?

ED SONDIK: Kevin used the word, I think it was validation before, and that was the first time actually I heard it and that was actually a concern of mine, that there is, I think, an issue here as to what the unscrupulous might do with their PHR. And I don't know where I came up with unscrupulous, we could think of lots of other words, I suppose.

But I think to me this is an issue and I think maybe has to go into the principles. I'm not sure quite sure how to phrase it but I think there is a responsibility not only on the public side but also on the health care system side to how to address this.

The other thing with the -- the other point in potential target populations, I would think that -- I thought this maybe came up at the last meeting, something about community health clinics. Medicaid population and so forth could be a -- this would be tremendously useful to this population and I would certainly endorse the pediatric population for the reasons that were stated before. This really could be a vehicle that eventually the entire family could get behind.

DR. BRAILER: We've actually been meeting over the past year with the leadership of the various pediatrics professional societies and children's hospitals in a group called the Pediatric Steering Committee exploring their contribution to health information technology and health information technology contribution to the unique care environment in pediatrics. So I think this would be something that they would welcome as a cause and I don't know, Gail, if you've spoken that group or if this is just a line item recommendation for a target population that hasn't been analyzed yet.

GAIL MCGRATH: We've had some conversations but not a lot. But we certainly view that as a very viable target population.

DR. BRAILER: Jonathan?

DR. PERLIN: Let me add my appreciation of the articulation of the principles. I think they are very on focus. Let me challenge the group to articulate that which I think is necessary for the up take of this. It's -- [unintelligible] said they're doing a great job of launching personal health record and the opportunity for us to combine forces great but I always wonder in terms of the incentives to drive this. What is the value proposition for the different players involved?

Let me give you a couple of examples, emerging personal health record, we turned on on-line prescription refill in the first week, a couple 100,000 hits to do that. So the ability of someone not to make a phone call was very powerful in terms of being an incentive to use that as a tool. The ability to schedule appointments. I think all of us health care experiences, want to pay tribute to the Secretary's admonition to do away with the clipboard, having to rearticulate the history, which is just that -- it's history, that which has gone before. It's constant and should be available and that makes sense but at another level and I know this gets a little bit on the margin of a very charge, what are the different relationships of the entities that actually make the different players who want to actually stand up to health record, use the health record, and I think putting on a couple of different hats; if I were a physician in private practice, I want to have a discussion with my patients about abnormal lab values, really probably would like to tell them everything is okay.

If you knew more information on normal values, here is the website and so one can imagine an image where there is a relationship that is built in my health record where I can get this information back to flag for further destruction, perhaps with [unintelligible] to the previous discussion, structured messaging around that but also a linkage to information about the normals so there is value added in a sense to the patient and/or lay caregivers and the clinicians.

So I think again the challenge is not a technical one but the alignment of incentives, the value proposition of different players have to get involved to make this thing viable and just really

without getting beyond the specific charge to us for this to get traction I think we have to articulate how this helps the different entities.

DR. BRAILER: Kevin, go ahead and then we'll turn to Mitch.

KEVIN HUTCHINSON: From the work group standpoint, we kind of took the approach that in the previous conversation in chronic care improvement, in consumer empowerment, these are the tools that would need to be integrated into the relationship between the physician's office as well as the patient to be able to also facilitate the programs that would come out of the chronic care improvement group and what elements need to be in those tools to support those other work groups as well.

DR. PERLIN: I agree with that statement but I think that as one moves to the concrete recommendations at the next step I think it will be worthwhile to articulate specifically what value accrues to whom by doing what.

Let me give you an example and this is totally conjured up but the image was used of a bank, an on-line banking where the information is secure and there is a set of rules around which we allow our information to be trusted. Imagine if I'm an insurer and I'm taking care of a diabetic population, then maybe there is some discount on the insurance premium the patients are receptive to information on self management. Maybe there is in fact some incentives, as Lillee offered earlier, some incentives with exercise and filling out this information so there is actual value in creating the information so that when that patient goes to someone else who has access to the information that is ultimately paid by this insurer, that information leads to a more rational use of resources ultimately achieving better health outcomes.

I think that sort of value flow is not only fundamental but as we get to additional discussion busy interrelationship of the chronic care management, electronic health record, the personal health record and the sustainability, I think that's really going to be what allows us to generate image with momentum to make it real.

DR. BRAILER: Dan, we'll turn to you after Mitch. Let me just respond to that. The slides 6 and 7 which really raise these questions of models and target populations is a theme that we have now heard in two work groups and we'll hear in two more and clearly the groups have the challenge of going off and scoping who will get this and in what way? So we can begin having a rational discussion but on the other hand we can't do that in a vacuum outside of the actual recommendations and what we are able to do and change.

So it's our hope that this meeting represents a key pivot point where the groups can go out and turn themselves to what needs to change to get this done and if they do that, refine who the populations are. Or what the delivery models would be that set that context. So it's my hope that before we leave this discussion that the community members will give any further advice or thoughts to the work group on slide 6 and 7 so they can go and close their debates about models and populations.

We've heard some good discussions about pediatrics, but these were not meant to be exhaustive, I don't think. I think they were meant to be suggestions so we could do that so they could go off but their obligation is to come back to us and say for what population in what way in what recommendations need to be made so we can achieve this. Mitch and then Dan.

DR. ROOB: If you choose a pediatric population I would kind of make a couple of points on that. First of all, about 50% of the births in America today are funded by Medicaid. So you will find that one way in the -- that you may solve the pre-population issue is through MMIS systems today that have a fair amount of this data already resident in them. Claims processing systems exists for most states. So if you want that population, CMS, I think, has some ability inside your new budget bill to fund some pilots for that, at least I'm hoping that they do.

And I would also add that from a care standpoint that population ages, the discontinuity of care that exists in that Medicaid and ship population is substantial. We see that population over lifespan changing primary care providers much more regularly than we do a privately insured population. So having that personal health record for that patient population, I think would add value from a health care standpoint and actually maybe be easier to implement than perhaps you might think.

GAIL MCGRATH: We have actually are hearing about different programs in different states that are targeting the Medicaid population and you probably can speak to that better than I can but it does sound like there is something already going on.

MALE SPEAKER: There is in a number of states. It's already started. So we can get you more details on that as well. But it is an area to look at.

DANIEL GREEN: I just wanted to go back to the earlier conversation about incentivization of the different groups that impact on this. We took our charge to heart with the first word in the charge, it's consumer. We saw our role as focused on the consumer to get the consumer buy in. So we, in our discussions, we talked mostly about what's in it for the consumer. And so that would be the primary incentive.

The other participants in the process, especially the providers and the payers, one of their incentives, maybe the primary incentive, in this particular case would be that they are satisfying their patient, their customer, and thus stepping out in front of maybe their competitors or are certainly improving their relationship with that consumer by providing something that is seen of real value to the consumer.

DR. BRAILER: Chantal?

CHANTAL WORZALA: A little bit of a change in topic but as we think about recommendations that might come out of the group, I'd like to raise the importance of the basically single way to authenticate patients and match patients to their records. I think this will be a growing quality issue as health information flows through the system, making sure that you have the right records for the patient who is in front of you. If you don't have the right record, there could be pretty serious quality repercussions, both if you're using the wrong data or if you're missing pertinent data. I hope the work group will think about what kind of recommendations in terms of actually addressing that key issue could potentially be put forward.

DR. BRAILER: And I would comment that commission on systemic interoperability had a substantial discussion and set up recommendations of the question around patient authentication. It could be important input into that discussion. Other thoughts or comments on this work group's activities? Lillee?

LILLEE GELINAS: Just a quick process question under the potential target population and what Bill and John were just talking about. It is when we're talking about the VA and DOD database, is that a potential target population or is that -- did you ad one there or is that a test case you're talking about? I thought it was a great idea. I want to give you positive reinforcement.

DR. PERLIN: It could also be a breakthrough model.

DR. WINKENWERDER, JR.: Sort of a government sponsored -- government sponsored health care population model.

DR. BRAILER: We are already well along with both of your populations having access to their medical history.

DR. WINKENWERDER, JR.: Right. But where a saw some added value is the ability to connect or for physicians again...

DR. BRAILER: Reach out.

DR. WINKENWERDER, JR.: To reach into this and for our populations to use this and for us to advertise its use and to look at the data and interoperability standard. Some of the things that are barriers for others if we can create a model that works.

DR. BRAILER: Could we turn to slide 6? So this could be a potentially other way to deploy. We talked a lot about using federal buying power, contracting power to help make these things available and this is one of those avenues that could be pursued.

While we're on this slide, I do want to just ask if there is any community comments because this going to be a critical issue in this work group about how they might actually think about achieving the result for the target populations. This question of independent PHRs versus payer, employer, or health plan sponsored versus ones that are existing through health information exchange efforts and potentially now through a fourth vehicle, any other thoughts here would be appreciated as they go to work after this meeting.

DR. WINKENWERDER, JR.: Just to comment on that, there is probably a lot of invasion out there with the "independent efforts" and it doesn't -- probably not good to try to stifle that. On the other hand, I think that the notion, or the need for consumer confidence and trust, openness, accountability, all of that is so important in this that having a sponsorship of broad sectors of American society, institutions whether unions or employers or -- is important and really important. So I'd sort of lean towards the something that was sponsored by bigger institutions that were accountable to the public.

DR. BRAILER: Doug?

DR. HENLEY: I hear there are some -- picking up on that there are some large systems already besides those that are into the public sector that are totally interconnected electronic health record system that is where you could envision a model of using data from those -- that EHR system prepopulating data into a patient health record. As another model, going from EHR and PHR and back and testing that model as well. Particularly --

DR. BRAILER: You're saying that's already in use where we could look at that?

DR. HENLEY: No, I'm saying that there are plenty of broad coalitions of practices that are using a single EHR.

DR. BRAILER: Yes.

DR. HENLEY: In the private sector and so another model to test would be to, assuming they are certified EHRs, which is getting underway, we could test moving data from the EHR world into the PHR.

DR. BRAILER: Right. Very good. Any other thoughts on this slide or on this topic of breakthrough models? Tony?

TONY TRENKLE: I think one thing regardless of which model we choose, I think the whole issue of portability of PHRs is extremely important. I think as you see more and more employers using PHRs as a way to improve employee wellness and other types of outcomes, I think that as people move from employer to employer, or move from different plans, I think it's important that we establish portability not only the interoperability between EHRs and PHRs but also between PHRs.

The other thing I'd like to point out is if a number of these are not covered entities under HIPAA, we need to look in terms of what are some quote/unquote standards or certification minimal principles, I guess, or certain types of standards that need to be done here to make sure that the ones who aren't covered entities also adhere to the HIPAA guidelines as well.

DR. BRAILER: I'll ask the work group to take that up. I think that's already been discussed. We'll continue that.

Other thoughts on this slide and let me just turn it back to the broader discussion of this charge. Turn to the co-chairs. Do you have sufficient thoughts, guidance, from the community members to be able to go off line and again, the effort here is aimed at having substantive and specific recommendations during the meeting in May so we are able to give advice to the federal government or to other players about what they need to do to achieve this short-term goal within the 12 month period we set out in January.

GAIL MCRATH: I think we do, David, but I'd like to ask a question. When Bill was talking about possibly the DOD, is that something that we would make a recommendation to that or is that something that the contractors would just start looking at? I mean sometimes we get confused about what our role is as the working group versus what the contractors are doing.

DR. BRAILER: Let me speak to that question generically because this came up quite a lot in the deliberations of all the work groups and then maybe we can turn it back to this individual case. The work groups are not management bodies. They are not implementation bodies. While we've asked for a huge amount of people's time to participate in these, some people have been telling me the work groups feel like they are full-time jobs now, we recognize that everyone on the work groups have a day job and there's other priorities they have.

The implementation tasks are left to the Office of the National Coordinator, federal agencies that are involved in the lattice work of federal efforts to support health IT or to the contractors that

either employed specifically supporting health it or again other tasks that we are re-tasking to support the health IT efforts.

So we view the work groups in the most strict normal form, as advisory bodies, and again under the strict normal form, the advisory groups would make advice, the work groups would make advice. Here this group deliberate and act and transmit a recommendation to the Secretary or to again, to others.

But in this case we are acting somewhat differently and this is where the confusion lies and I'll just highlight those. We have a number of federal people on each work group to be able to bring both to the work groups a current amount of information about what is happening or what could happen, and to have the federal employees understand right from the get go what the needs of the work group are to achieve the results. So that when we are looking at recommendations or advice, we are months ahead of the process to be able to begin understanding what it takes.

Also, we are trying to support a process that allows these recommendations to be accelerated through the discussion not just to the federal government, but to private sector entities or others. Again, we view this Health Information Community as a steering group for many entities even though it's technically legally chartered as an advisory group to the federal government. And we'll respect that rule for the advice to come in but we do hope that payers or employers or health IT companies or providers will also take their key actions from the recommendations that are made here and I think it's our hope that you should feel empowered to make recommendations to others to do things.

So I think it is different, but in the end, the important work that no one else can do, that only the work group can do, is make technically informed recommendations that come here about what needs to happen.

So from that specific instance, if you want to treat something that VA and DOD does as something you like to see happen, you should recommend it. If you just treat it as a fact and the background that's part of your thinking but in the end is not a recommendation you make, that's still valid, but it's really up to the work group decide how to separate the difference between fact-finding and background information and forward-looking recommendations. So I think that's going to be true with all these and it's come up a lot and I appreciate the chance to provide clarity.

Thank you. Any other thoughts here? Okay. With that, we have concluded the second work group report. We have a lunch scheduled that would formally start at 11:30 but we'll start now at 11:20 which of course means we'll expect everyone back at noon. So we have 40 minutes.

And I'd like to also tell you the very good news that the cafeteria that is on this floor has been renovated and is now open. So you can help us in inaugurate it and it's just across the hallway. And I thank you all very much and we'll see you at 12 o'clock.

[afternoon session begins]

SECRETARY MICHAEL LEAVITT: Good afternoon to all of you. I know you've been busily engaged this morning and I'm sorry I was not with you. I was here in spirit, not in body. There are duties that were required of me at a place I can't turn down.

I do want to express appreciation for the work you have been doing. I know there is a lot of work that's been going on over the course of the last several weeks. I had opportunities to interact with the work groups and I know your work is moving forward. The reports that you heard earlier today, I did have a foreshadowing report and so I feel like I did not entirely miss those reports but I'm sorry I missed the discussion.

One thing I would like to mention before we get started on our afternoon's work, at our last meeting, I announced the creation of the Health IT Policy Council to help refine the federal government's action in responding to health IT issues as they develop. That council I believe as most of you know, is well underway now and will focus on bringing the federal agencies together to find and to facilitate recommendations generated within the community.

The second thing I want to mention is something that will directly affect our work. I want you to know that our group has been asked to undertake one additional very important assignment this year. The Katrina After Action Report called for the development within 12 months, of an efficient and effectively deployed electronic medical record or health record that could be used by first responders in the case of an emergency.

We all experienced this in Katrina. A million people displaced without records, some wonderful things happened with the participation of many around this table, proving that there is no reason this has to take a long time. But it also pointed out how crucial having a basic health record would be for first responders. This would not be a full-featured hospital emergency or electronic health record but rather it would be a standardized set of very limited number of crucial elements that would be needed in an emergency situation.

I endorse this call and in fact it was part of our after action report, field deployable electronic health records would be used in a crisis situation and I believe that developing recommendations for its achievement fits very well into the mission of the community and the progress already underway here.

I'm aware that the Southern Governors Association Digital Health Recovery Task Force is in attendance today and they have been working in this area and I'd like to ask them to continue their work. With this new goal that we have in mind and invite them to come back to the Community and reflect on their work with us and their context, in that context.

It will be crucial that what is developed in this electronic health record for first responders can be merged and harmonized into our over all -- I think it provides another good opportunity to create momentum. And it clearly is a national need.

So I wanted to mention that and lastly -- not lastly -- I'd to also to ask Dr. Brailer, or before I ask him to continue with the presentations, I'd like to take just a minute and express may personal appreciation to Dana Hauser for all the work she has done here at HHS.

Dana's has become a personal friend, a person that I admire. I'm on a long list of those who feel that way about her. She's leaving us after today and though we're certainly happy for her, and want to wish her all the best in her new endeavors, we are sad to see her go and I personally will be -- she's been extraordinary and in her efforts not just here but in her work prior which has been a very important part of linking into this. So Dana, please know my gratitude for your ongoing service and I look forward to working with you in other capacities.

So Dr. Brailer, why don't we proceed with our agenda.

Dr. BRAILER: Thank you Mr. Secretary. I will turn the members of the Community to tab 7 and we will resume with the Electronic Health Record Work Group which is chaired by Lillee Gelinas and Jonathan Perlin. We'll turn it to them. Lillee.

LILLEE GELINAS: Good afternoon and welcome back from lunch, everyone. It has been a tremendous privilege and pleasure to work with Dr. Perlin on this important work group. Our overarching message for you is we need your guidance. We need your guidance to amplify what you agree with, with what we are about to present. Verify the approach that we are going to be talking to you about. And wave the caution flag where appropriate.

But clearly, one word typified our group and that was action, to get on with it. And I'm really proud of the work group and what they did. So thank you to the members of our work group. Their tremendous engagement in this work was very, very quick at task and they jumped right in and I believe two members of our work group are here today in the audience. I'd like to acknowledge them: Carolyn Clancy from AHRQ and Pam Pure from McKesson. So thank you for joining us today.

The work group charges: the broad charge for the work group was to make recommendations to the community on ways to achieve widespread adoption of certified electronic health records, minimizing gaps in adoption among providers and our group would like for you to underline one word in that broad charge, adoption.

The specific charge of the work group is to make recommendations so within one year we have standardized, widely available, and secure solutions for accessing current and historical lab results and interpretations which are deployed for clinical care by authorized parties.

So why the lab? If you underline lab under this specific charge. Well, when we look at our background discussion that the work group had, there were three specific questions and it seemed so simple to put four hours of work into three lines. So my congratulations for doing that.

The three lines are Why lab? Where are efforts aimed? And what should be our approach? In terms of "why lab?" underline availability. Because the availability of electronic data and clinical relevance suggests uptake is quicker and clearly could be a catalyst for broader EHR adoption.

And where should efforts be aimed? And we suggest that you put a question mark after that initial goal of more broad than clinicians with EHRs. We're not purporting to answer that question for you. We are teasing that up for the group. But while the specific charge talks about those systems, our broad goal is to dovetail with PHRs and I'm glad we just had our conversations this morning around PHRs.

What should be our approach? Is it person-centric? Put a question mark there. Is it lab-centric? Put a question mark there. If the patient or the consumer owns the data or the lab or provider owns the data which is our current system, the definition of how to proceed really takes two different paths.

So, with that introduction I'm going to turn it over to Dr. Perlin and he's going to take us through our further contemplation around charges.

DR. PERLIN: Thank you, Lillee. And let me extend my thanks as well to all the members of the work group who did so much good effort in putting this together. Mr. Secretary, Dr. Brailer, all members of the committee, I think Lillee phrased the words that we really wanted to focus on which was adoption. Moving us forward and making this real, you know, the Secretary has charged us to action.

And on the next slide you see that we contemplated a number of models. I think towards the theme of really fostering adoption, I want to make sure we didn't exclude anybody, that we were inclusive of all mechanisms to be able to foster adoption of electronic health records.

And as Lillee said, laboratory was identified as one of the catalysts to drawing out what are adoption of health records. I used Dr. David Brailer's term here because in a sense it's one of the most aerodynamic elements. It gains flight because these are data that are born electronic and they're data that all would find useful to improve the rational use of health resources and certainly the quality and safety of the health care that is delivered.

So room for all to be involved in a variety of models, let me start at the top of the page. And one that is one we're learning about, with the work that's going on in the country, with RHIOs, it's being studied, but this is potentially a model that would support the patient-centricity where the information would follow the individual across different providers, across different environments. It's potentially a model where there is a self-sustaining mechanism for the health information exchange itself. Data from multiple sources would be available to different clinicians and in terms of the interface mentioned earlier, to patients as well with personal health record.

What are some potential alternatives? Well, since the data for laboratory tests are born electronic, doesn't -- wouldn't it make sense that there would be a standardized mechanism for what we're calling peer to peer communications, that is the provider with an electronic health record would be able to have a general electronic interchange with the laboratory which almost by definition produces an output that is electronic. So this would actually facilitate at one level the interface.

Now there is a third model that also exists, and this is a model of portals, web-based portals. In a sense, this is a window to information so that if there are multiple labs in the environment, a provider with need for the information could actually use this portal to look in and find the information, assuming appropriate mechanisms for identification of the patient, the definition of the architecture and some work that is yet to be done in terms of standards for authenticating and authorizing the use, and I'll just leave it that there are a number of policy implications in terms of that as well as of course the technical information.

What is less clear on that model is whether if I'm the doctor and I order a test for a patient, if the next doctor who sees that is patient would have access to the information I order. This would be one of those thorny areas we'd have to work out, but potentially with a portal type solution one would be able to look into the difference sources of data assuming the governance, if you will, were worked out.

Go to the next slide, you'll see a graphic representation to this, and so the standardized peer to peer is really the ability to electrify the relationship between the ordering clinician and the lab that is

supporting the particular test. And that actually would facilitate broader adoption because it would be among the easiest to achieve for this individual who have health records.

Let me turn to the RHIO on the right and I'll come back to the portal. On the right, the RHIO you see that the data could potentially be more patient-centric and follow the individual around different health circumstances including practitioners who didn't necessarily prescribe or order the tests for the specific patient across the hospital, across the other sites. A third option is the web base, this sort of opportunity to view different data sets that different labs may have produced, and that could be have very, very expeditious. We'll discuss later one potential downside, which is that it may be so expeditious that it's taken as too easy an alternative to actually getting to full implementation of the electronic health record and so instead of incentivizing and moving forward, actually serving potentially even as a disincentive.

Let's go to the next page. To get to these models, there are a number of enabling issues that actually interface not only with the other work groups on the Community but also some of the groups that we're interacting with. One is HITSP in terms of -- I'm sorry, the Health Information Technology Standards Panel -- which would help to review the different and contending standards and help us really rationalize the ability to adopt standards that would facilitate the broadest communications among the different actors in the healthcare environment.

The other supporting issues that are issues not unique to our discussion but interface quite nicely to the discussions we had earlier today relate to the identifiers of the different persons in health care. The patient specifically, the providers and the circumstances under which those individuals would have access to information as well as potentially other authorized care providers.

There are a number of policy issues that are conjured up in this discussion of information sharing and I'll just leave it at identifying that as with the other groups again issues of HIPAA and what is a covered entity come into play, and the fair and appropriate exchange of lab information under CLEA.

I'm going to jump down to the implementation of models and make the argument that for most rapid adoption I think, our group felt there were a number of different approaches and they were not mutually exclusive. Taking advantage of the environment, where there are some of these RHIOs and some are very nascent and others are actually very sophisticated and well developed, can we help to move things forward by using that as a vehicle either to further the adoption of electronic health records through the sharing of lab data, or can we actually learn from some of the RHIOs that may in fact be at that point and understand what some of the great enablers are in terms of fostering that sort of adoption, recognizing they're still somewhat rare and the broader environment does not have RHIOs.

We as a group feel that the peer to peer web portals offer certain advantages and the opportunity there to accelerate again is coming forward with a very standard space approach to the information sharing and that those two actually complement each other in terms of fostering the adoption.

I think it's important to understand the value proposition. In VA we have a bit of an advantage which I'll just state very [unintelligible] is that we are both payer and provider and so I think the input of my co-chair's comments and your role in the other VHA bring together hundreds of thousands of voluntary hospitals are particularly important. Lillee?

LILLEE GELINAS: We talked about this and while we flipped it to the end of the presentation here, on this slide here around enabling issues is around the business case because our work group constantly dealt with the issue, who is going to pay for it? If there wasn't 5 minutes going by and I'm seeing everyone's head shake. I'm just dropping the ugly off in the middle of the room, and there was a lot of great discussion around that.

However, we know from other initiatives that impact can be measured. We know that for a fact. We also know that value proposition may not be in just dollars, and I think our discussion this morning from the Gulf States Governors Association certainly made that clear around impact and value can be in terms other than that just dollars. There are social impacts. There are other than economic impacts.

One piece that helped our group having this rich work group, and Mr. Secretary in your first presentation to us you talked about in work groups that we would cast the net widely and in this particular work group, Dr. Perlin and I have been fortunate to have tremendous representation from a number of different entities to cast that web broadly. And we've been able to consider work that's already been done. You may have received by e-mail and not had a chance to read yet, but the health care financial management association that's been done on overcoming barriers to electronic health care record adoption, and Dr. Brailer was key in that particular work.

So we may not have to reinvent the wheel here. It's considering what tremendous work has already been done and talking about what is the value proposition already established. Can we apply it in the private sector? We've said and Dr. Perlin your job is easier because you are payer and provider. That leads us to open issues and I think you were going to talk about our pithy discussion around broad versus deep.

DR. PERLIN: Great. Thank you. And really some of the questions are very straightforward and in deriving from the questions of what sort of model. And so which environments? Were there mature RHIOs or hospital based systems? Which sorts of environments support the charge of really deploying electronic health records as expeditiously as possible?

Again I come to the point where -- observation in the group is that these are not mutually exclusive but there is an opportunity to learn a good bit about the RHIOs and the rest of the environment and that will be actually some of the reporting into the group next time. I think it's fairly -- I think those of you who are familiar with the concept of RHIOs understand some of the interrelationships there and I think it's also very intuitive to look at the sort of standardized peer to peer, where it's lab to doc, doc to lab, or other clinician as relationship. The other one is and perhaps the -- one of the most intriguing is the web portal which could actually on many senses superimpose on the standardized peer to peer but also superimpose on the RHIO. And that's a strong positive.

The group had some concern, though, that its ease of being able to click on and get that information would have immediately utility but potentially discourage individuals from going further in terms of building the full electronic health record. Our focus, purposefully, because of the nature of the lab data itself was to limit the initial discussions to the lab data. But the question was, should we limit this just to providers who have an electronic health record already? And obviously that would be fairly limiting and I think that would discourage the aspirations of all of us.

But you can see quickly that question leads to, okay, if not just individuals with health records, is it all clinicians, and we haven't excluded purposefully or otherwise, that the patient and the personal

health record, I think our discussion this morning was very valuable in terms of really dovetailing the idea that the data should be interoperable and authentication rules etc. should obtain, but once you move more broadly to questions that really tees off is your goal lab-centric? That is, focus on the data or is it person-centric where the data follows the individual regardless of the context?

And then simply questions of which data sources would be appropriate for some of these early pilots. Ultimately how inclusive can one hope to be? And how do you actually take it from concept to pilot and ultimately to scale?

Well, if those are some of the questions that are outstanding, there are some thoughts on next steps and I'll turn back to Lillee for those.

LILLEE GELINAS: We as a group, declared consensus that our March work group meeting that will be occurring here in two weeks really needed to focus on a couple of very concrete concepts here. We want to define the environmental characteristics for successful deployment of recommended models. We asked the staff to conduct a rapid environmental scan, explore RHIOs and hospital based processes that are currently available, explore governance, financing, value propositions and successful RHIOs, and we look forward to a presentation from AHRQ at our next work group meeting on the work that's underway there. Exploring market contexts that drive specific solutions, whether it's RHIOs, web portals or direct linkage to laboratory results. So using the medical model of the CAT scan we want an environmental scan so that can inform our discussions and decisions further.

In addition, we know we need to identify key components of a patient driven easy to use secure authorization process from both technical and consumer perspectives, so we'll be considering the issues related to that issue. And we will consider both technical and consumer implications of optin versus opt-out patient choices. We haven't talked about opt-in versus opt-out patient choices so far today. So I look forward to all of you around the table helping us as we consider that issue.

And finally we want to provide further recommendations for rapid deployment of models. We've tried to not use the adopt word too much here. Rapid deployment is coming into our vocabulary a little bit more. But we thought in order to move clouds to clarity that in this area so much work has been done around electronic health record work and implementation thus far. And we have landed a concept that I think Dr. Perlin and I now understand that we didn't know when we sat together last October for our first AHIC meeting and that is that there is managerial evidence of better performance and there is scientific evidence of what works.

So there is the sociology and the science. And it's going to take both. And perhaps some initiatives there far have only addressed perhaps the sociology or the science.

But as you see, this last bullet there about providing further recommendations for rapid deployment of models, in the private sector, we know that there are a number of initiatives now taking place that are facilitating rapid adoption. And I had shared with our group one that is happening in VHA in January of 2005. We only had a few hospitals of our 1300 plus acute-care hospitals with rapid response teams and because of some things we've done this year we now have over 500 in place in less than a year.

So this notion of perhaps -- and you talked about it, alpha and beta best practices. Test them. And then go grand scale. And we've seen in the private sector that work with a couple of different initiatives. So, with that, did that cover our next ups do you think?

DR. PERLIN: I think, we certainly thank you all the input. I think this group, its name, Electronic Health Record Work Group was overwhelming given the goal here to move to electronic health record forward and obviously has a great deal of interfaces with our fellow work groups, with other entities, as we mentioned. And again, just to summarize, the laboratory because it's born electronic and how to use that as a lever to move the entire agenda forward in a way that really is inclusive of all. Thanks.

SECRETARY LEAVITT: Thank you. Could I ask that you take each of those three options and talk me through it from a consumer point of view? If I got a lab test...

LILLEE GELINAS: The models?

SECRETARY LEAVITT: Yes. Would you just walk me through?

LILLEE GELINAS: Can we go back to that slide that says potential models. There we go.

DR. PERLIN: Actually do me a favor. Go to slide 6, if you would. Okay. Let's say you're the patient and come to me and we order a cholesterol test. Let's start with model A, the standardized peer to peer interface. You come in to my office and say okay, it's time -- we've been working out a great deal with emphasis on that and we want to check the cholesterol. So I order a lab test and I order it from a specific laboratory. And ideally if I have an electronic health record, I order that electronically and it comes back from the lab corporation to me as your doctor and that closes the loop. Unfortunately, what it doesn't do --

SECRETARY LEAVITT: This goes back to you as a physician? It doesn't go back to a electronic medical record...?

DR. PERLIN: If I have an electronic health record it could come into an electronic health record, yes, that is correct.

SECRETARY LEAVITT: So it would be either a record at your clinic or it could come back to you just personally depending on how you would receive it.

DR. PERLIN: That's correct. It could be part of a larger group or an individual office but into your electronic health record ideally but trying to make electronic interchange instead of facts or anything else. Make that electronic so the data comes back into a health record electronically.

SECRETARY LEAVITT: It goes back in and fills up the boxes with the right piece of information?

DR. PERLIN: That's right. The -- I'm going to just -- obviously that would be very, very straightforward in terms of the relationship of the two entities but when we go to Dr. Brailer's office, if he doesn't have interoperable electronic health record as part of our group, he may have to order that test again, and that's the challenge there.

SECRETARY LEAVITT: Okay, so he would not be able to get it from you. Presumably he couldn't from the lab corporation either.

DR. PERLIN: That's exactly correct. There would not be clarity just now if it were on paper of him being able to call-up. He wouldn't -- in fact -- he wouldn't know what he doesn't know. He wouldn't know the lab has actually performed that test.

Let's come to model 2. The portal. And let's say that I've ordered the general overall cholesterol level and then go to Dr. Brailer's office and you get a -- and he wants to talk to you about exercising and cholesterol and says, what tests have you had? And you say, I was over in Dr. Perlin's office. He could get on the internet and get on this portal and say, "Gee," -- with appropriate authorizations, authentications of who he purports to be, go in and view and say well, lab company x performed a cholesterol on you and he would have that information so if he went to order another test he wouldn't order a duplicate test.

SECRETARY LEAVITT: Presumably would the portal be a port that I, the patient had chosen? Would it be a commercial portal or --

DR. PERLIN: In this instance the portal would be something available on the provider's side. We're not specifically seeking to exclude the patient's personal health record. In fact one sort of open question here is that there would be no reason, theoretically, that the patient with the appropriate personal health record couldn't also use the same sort of portal to zoom in and say okay, I want to see my lab but we were just sort of taking it one step at a time. In fact, today was very informative in terms of understanding where the personal health record group was going.

SECRETARY LEAVITT: Let's assume I have a favorite portal company that I have my e-mail with and I have some music I buy and I tend to do some electronic shopping there and I have my instant message and I keep my photos there and they have a window that says health record. And I have registered and that's the portal that I would like. Is that part of this vision?

DR. PERLIN: That is potentially. I mean it's not specifically. But the idea is you would have a sort of generic viewer and be able to get the information. What you're describing is a vision that we had some discussion about more broadly earlier which is what kind of clients you have.

Someone used a really good analogy earlier. Do you go on-line to bank with your favorite bank? Your personal bank? And you might have a different account with another bank or -- and do transactions through their viewer or do you actually manage your money in one of these programs, I'll just use the name Quicken, that actually goes behind the scenes and reaches out to the same companies and gets that information, and while not necessarily part of this specific vision, it's a sort of derivation that would allow one to get information that lives somewhere else.

SECRETARY LEAVITT: Let's say that portal was Quicken for health care. And it could -- I would assume it would have established it would use the AHIC standards and go off to the lab company and say -- or someone could say Mike Leavitt ordered a lab request there and send it to this place on my Quicken for health care record.

DR. PERLIN: And your Quicken for health care is an absolutely fabulous vision. The challenge we have at the moment is that we need to set up the relationship with the on-line bank in the first place and so while I endorse conceptually the vision, our thinking was really more can we set up

the relationship with the banks so we can transact on-line before we put the program, the Quicken for health care in between. But it's a great vision.

DR. BRAILER: Perhaps just comment, as you recall, sir, the discussion we had in the prior work groups about the medication history actually is quite like that model. Perhaps not a downloadable software product but because prescription data is so highly concentrated and so few hands already getting access to it in a unified way is not a significant challenge. We've proven that with KatrinaHealth.

In this case, where we have labs highly stratified across national laboratory companies, local regional laboratory companies and hospital doctor office laboratories, the consolidation and unification of that data is a massive challenge for the industry. So the focus here is how do we get the data to the doctor and thinking that the next step to achieve this is then to take it out to the patient to follow that medication solution once we can consolidate it.

SECRETARY LEAVITT: Are you speaking of future -- are you talking about past lab tests or talking about future lab tests? Because presumably if every lab company ultimately concluded there was a series of standards that they needed to adopt, over time, that wouldn't be a challenge, would it?

DR. BRAILER: There is a theoretical idea here of the peer to peer interface that would allow any provider of information to share it with any accessor of information.

SECRETARY LEAVITT: Which could include a Quicken for health care?

DR. BRAILER: Well, that's not a peer to peer model. That in fact is a brokered model where there is an entity in the middle that is determining you are who you say you are and the people you're collecting in that case, banking data, from you have an established trusted relationship so they can't spoof you or get your data in another way. So there is a central agent acting in the middle.

SECRETARY LEAVITT: I guess I'm just not getting the portal thing.

DR. BRAILER: Can I just -- one way to think about this is rather than 3 options, there is really a two by two table here. There is an organizational aspect and a technical aspect. The organizational aspect is, is this a business-to-business, lab to doctor, where there are multiple labs providing data to multiple doctors or multiple hospitals, or is it something that is hub and spoke where there is a central broker acting, maybe as a Quicken, in this case they're regional models, that comes together and one place that clearing houses all the data.

Superimposed on that are two technical models. One is this peer to peer where the data is highly structured and standardized so it literally ends up in the electronic health record with the same content, form and usability that it would if you originated it, or there's the web portal where it's not standardized, not structured but you can view it, touch it and feel it but you have to know which search engine to go on. And those are combinations.

You can have the web portal in a regional model, where you can get one access, one view of all the lab data for one patient regardless of who originated it, or you can have it in an enterprise model where each lab, each hospital can have a portal and you have to figure out which portal they have. Same thing from peer to peer. You can get the data transmitted from a lab to a doctor now. That's

happening. Or in a structured way from a lab through a switch to whichever doctors are supposed to get it.

So there's really two aspects of this question here. And they got consolidated down for simplicity sake, because ultimately this is where the world is playing right now. It's not living in the two by two table. This picture.

SECRETARY LEAVITT: Other comments or questions?

MALE SPEAKER: Do you get this -- do you have that data because you're the payer or the provider?

DR. PERLIN: In this standardized peer to peer, because you're the provider.

MALE SPEAKER: But you guys today get that data because you're the payer or provider?

DR. PERLIN: I'm sorry, you mean the VA specifically? We built this as a clinical information system so it's really there because of the provider function.

MALE SPEAKER: Couldn't you get this too -- this is the Secretary's point -- from the payer? Couldn't the individual customer get a claims data, get that claims data and get that through the payer? Wouldn't that --

DR. PERLIN: I think that would be the record of what happened but probably not the lab result itself. It would also inherently have, I would suspect, some good degree of delay. It would have some delay.

SECRETARY LEAVITT: Is your question, Mitch, whether or not you could attach copy of the electronic record to the bill?

DR. ROOB: Well, couldn't you --if you're trying to get an aggregator and aggregate to your point right up of that information, the payer's going to get that eventually. Couldn't you get that --

DR. PERLIN: No. The patient gets very little clinical...

DR. ROOB: But you get the fact of the test is performed.

DR. PERLIN: Yes.

DR. ROOB: So you could -- could you connect the lab -- I mean, the lab data is going to get -- could you connect the lab data to that test and therefore be able to populate the Quicken version of the health record?

DR. PERLIN: So if I understand your question correctly could you use the fact that the health care ultimately is paid for, attach it to the paying function and then and create a mechanism for bringing the information together? Again, I think that's -- I understand the logic. I think in practical terms it would be somewhat difficult to operationalize. For instance, I might order a bundle of test and the pair would pay for the bundle but you wouldn't know the discrete elements within the bundle

and so once again I think it would be a loop outside of the relationship and indeed we don't typically share the basic lab data with the payer.

SECRETARY LEAVITT: Are there other comments? I have a question. Yes.

MALE SPEAKER: I think traditionally one thing to point out is the standardized peer to peer interfaces hasn't traditionally been standardized. And if you think about the peer to peer interfacings that exist today, the difference between a portal and the peer to peer interface is it's usually a 1-1 which I think Dr. Brailer mentioned where a lab, whichever physician ordered the lab test, the result is going back to that physician and that physician only. Through the ability of an EHR or some other mechanism and that physician is able to see it.

In a portal model if I'm understanding your diagrams correctly, actually it would go back into a portal which any physician providing care to that patient could ultimately do a query and see what results, whether they ordered that test or not, and they would see the results of those tests that have been performed, to prevent multiple tests from being performed and ordered by multiple physicians because they are unaware that the test was performed the day before by another physician.

SECRETARY LEAVITT: Does this begin to -- let's just roll this forward for 5 or 10 years and assume we've made lots of progress we haven't yet made. And we live in a world where electronic health records are much more common. And that people -- that we've got all the standards we need and that the question now is, how do we initiate and determine who keeps our electronic health record?

I assume I could have -- a payer could do that. They've got the information, they might have to link to the data and not have to keep it all on their database but somewhere there will be a way to assemble that information because the payer will have access to it.

If I'm a provider I've got it because I am a provider of some or all of -- if I'm a VA patient, I probably have 90% of it. If I happen to be somebody else, I may have a good share of it, but I may choose to have my provider as the utility to where I get that service, or I might have a Quicken for health care where I could assemble it on my own. Are we -- do we envision a world where we would have that choice, or do we envision a world where that function would begin to consolidate in one of those 3 areas?

DR. PERLIN: You've asked really the pivotal question in our presentation, which is whether the data is lab-centric. That is, is it owned -- does it reside in the number of sites because it's a lab element produced by a particular lab or does it in some way follow the person so that the person moves, the person goes to different doctors, that it follows them. If they want to determine -- if they want to have their personal health record, do they control.

Second question: who has access to it? And so those are some of the additional issues. The value of the electronic health record from our experience is that if I have chest pain and I show up at the Washington VA and I'm giving a talk in Baltimore tomorrow and I have chest pain, they can actually know my past record and so they don't have to know which doctor I particularly went through. They just have to be able to follow the person -- me -- and be able to retrieve the information. So --

SECRETARY LEAVITT: What if you had gone to -- what if only a portion of your health care was done at the VA? What if there were things that happened at another hospital at a different or less enlightened time in your life -- would that be there?

DR. PERLIN: That's the problem because just as today, it's the clipboards you wanted us to get rid of. Today is that I would have to recapitulate every hospital I've been to and every test I've had and I'd have to identify to someone where that data lived, or do we move to a system that says okay, we know who John Perlin is. Is there a way to gather up the bits and piece that exists around the country and pull that together into a coherent record? That is something that -- certainly in VA, we have the VA information but if I got care outside of VA, today we can't get that. We can't identify the individual and pull in the information that is relevant to that individual. But if I knew that the particular patient had been to Dr. Smith who used Lab X, I could actually call up Dr. Smith or Lab X and potentially get that. So that's the sort of lab centric model versus the person-centric.

## SECRETARY LEAVITT: Doug.

DR. HENLEY: In my response, Mr. Secretary, to your 5-year vision would be that all the people that you described, the provider, the patient, the lab, whatever, would have access to that information. If David is the patient and he has a personal health record and I'm his physician, then that information should be sitting in my EHR so I'll have it readily accessible whenever I need it or other providers need it and I may want to send that information to them or whatever or share it in some fashion. David should have it in his PHR, if he has a Quicken web portal somewhere to store that data, that's fine. Certainly the lab or pharmacy should have that data where they are, so when David goes to the pharmacy or whatever needs to look it up.

But I think the elephant in the room here is that we are talking about data that has already been vetted and now is quote part of the past history. What is of concern, I think, to certainly physicians and other clinicians and I think of concern to patients and consumers is, what do we do with the data that was just ordered, has been completed in the lab, and hasn't yet been vetted in terms of an abnormal value?

Should the patient have free and open access to that positive HIV test that I ordered, and yet there hasn't been a conversation between the patient and the physician or other clinician as to what that test means because it's abnormal. Once that conversation happens, and therefore it becomes part of the past medical history, then it should be available freely to the patient, the provider, other parts of the system. But until that gets vetted, assuming that it's abnormal, that conversation has to occur, I think, between patient and provider before.

SECRETARY LEAVITT: I have never thought of that.

DR. HENLEY: So that's the a bit of a conundrum.

SECRETARY LEAVITT: I had never thought of that. That clearly is a conundrum. We need to discuss that. I think I was still asking a slightly different question. I can see once we begin to see standards develop, I could see an economic -- a set of economic incentives where CVS, where I buy my prescriptions would say, if we got their electronic medical record, they are always going to shop with us. And consequently I think I want to be in the medical record business and we're going to offer free electronic health records because we think it will be create an affinity that will be important.

I can see my clinic saying, if we have their electronic medical record and we control it, they will always want to stay at our clinic or in our health care system. I can see my insurance company saying, if we have their electronic medical record, they'll never want to leave us as a policy holder and that -- and I can see my internet provider, I can see my power utility. I can see just about -- I can see the post office. I can see a lot of people seeing an advantage to providing these electronic medical records because of the connection it would create.

Now let's just assume for a moment that I -- that that was the world we lived in and I wanted to change health care systems because I was unhappy with whatever health care system I was in and they had my -- I guess I'm asking a fairly basic question that maybe the others have thought through. But where -- if it's indigenous to our health care system or our provider, help me out here. Have other people given this? Daniel and then Kevin.

DANIEL GREEN: When I think about it, I look at sort of three things. I see a difference between the record and the information. I don't see why there needs to be any change today -- from today as far as who owns or creates and owns the information. I think we're asking for another level of complexity we don't need to get into. Your doctor has information. The hospital, the insurance company, whatever. They have information. The electronic health record is the thing that makes that information useable outside of the doctor's office. And then there, yes, then there can be competition as to who has the best or most useful, efficient, health record for different purposes.

Finally, though, there needs to be a mechanism, sort of like Google that says, for Joe Johnes these are all the places that there is information, medical information about Joe Johnes. So when you make a query out there to pull together, to compile an electronic health record you're not complete until you go to all these places and then of course there is all the rules about who can have what information and that makes my head spin.

SECRETARY LEAVITT: I get that vision. I can see that vision because in some respects -- well, I can see that vision. The question I have is that when I decide to change -- that defines a world where the individual initiates the creation of their electronic medical record and controls and owns the information and it's accessible at other places. And I think that's a very important --

DANIEL GREEN: Controls the flow of the information, not the information itself, perhaps.

SECRETARY LEAVITT: I guess that again gets down to who owns the record. If I -- I never thought about this problem with a test I had -- my doctor hadn't explained to me yet. Do I own it before he explains it or after he explains it? I hadn't thought about that. Let's go to Kevin and then back to you, Jonathan.

KEVIN HUTCHINSON: What you described is very much the transition that the financial world went through, as you know. So if I'm a consumer, it's if I want to use my bank's website for on-line banking, then I know if I become unhappy with that bank and I'm going to switch, I'm going to lose all those records unless I print, go back to hard copy. They are not going to port over those records unless I choose to use a Quicken or Microsoft Money to be fair, since we are talking about the two products, that has integration to the banks as well as my investment banks, and then as I move from financial institution to financial institution I don't lose as long as that institution also supports on-line banking, I don't lose any of my data or any of my conductivity or capability to see my history or anything else. And I think at the end of the day it would be the consumer's choice as to -- they're

entering into this world of the personal health record because the diagrams you see here are focused on the physician view versus the patient view. Other than the personal health record represented in accessing your RHIO.

That information I choose how I want to gain access to it in a perfect world. So if I want to use a client server on my laptop at home that's integrated to my health care organization, that's great. If I want to use CVS who is supplying a free personal health record I understand there's some limitations to that. They may not have access to all the various different networks that have information on me. It may be a much more limited record. But I think that's ultimately going to be the consumer choice.

Representing the labs on AHIC I know that there are executives in some labs right now jumping up and down on the other side of that camera so I need to say a couple of things because otherwise I'll be getting phone calls all afternoon.

The lab industry has been supplying, as you know this technology to physicians' offices for quite sometime but it's not integrated into their work flow, and that's the biggest challenge. It's turning from electronic to paper. So they get it, there's a terminal, it's provided, they view it, they can even call back up the order but it's only for that physician that placed the order.

If you're really -- if we're going to close the loop on this process, one of -- the biggest challenges of this particular space, is the efficiencies that the labs are most interested in is the order process, and that order process is not been a standardized way on a lab by lab basis or nomenclature on information that has to be submitted and so orders are still going paper. Results are coming back electronic. And I would challenge all of us as we look at this particular process, especially as an EHR subgroup that we focus on the entire lab process of how we get orders electronic and how we receive the results as electronic as well.

## SECRETARY LEAVITT: Jonathan?

DR. PERLIN: I think Kevin's points are extremely well taken in terms of completing the entire cycle. Let me address two things that I think are on the table. One is you offered a example of you switched doctors, dissatisfied with one, want to go to another. You actually would have the control to turn off -- Dr. Perlin is no longer authorized to view your records. You've switch your care to Dr. Brailer. That's a patient control switch. That's your authorization there.

The second just, because it's sort of intriguing is we hasn't anticipated but we faced this issue in VA with the personal health record of having a patient potentially discover something that was very significant before they had appropriate counseling. We actually resolved that with a business rule that if there are things like new diagnosis of cancer or HIV or something of that sort, then that data doesn't go forward until the physician has indicated or the clinician has indicates they had provided counseling. So we actually created a business rule to work around something that was novel in the sort of relationship.

And then to the third, which I think is the exciting vision of closing the loop. What are the dynamics that make this work in the world? Why does the patient want to play? Why do the providers want to play? Why do the labs want to play?

Well, for the labs, you said that their costs of doing business increased because they get requests for labs, a phone call here, an e-mail there, a lab form here, and it's just disorganized. To the clinicians on the receiving end, they get it back but it doesn't enter into their work flow and it may come back in a variety of forms. And to the patient, there is the patient -- poor patient there playing phone tag trying to find out what the results are.

So imagine the analogy that I think most of us now have had experience with on-line banking or that sort of thing and that the image out there is can the patient who gets care in one environment have the results available to another clinician in another environment and to themselves in a third environment? Well, maybe the insurer actually gives the patient an insurance discount because they have a health record and they share their health record with their insurance company and the insurance company gives that patient information about better control of their diabetes or exercise and nutrition.

Maybe, in fact, the lab's life is easier because they are not receiving everything on bits and pieces of paper and phone calls. So the opportunity to port that information back not only to the doctor but to the patient and provide a service that says, okay these are normal tests. Here is what a normal sodium means. Here is what a normal potassium means. But there is a trigger alert for the doctor this test is abnormal and needs counseling and actually simplifies the clinician's time by focusing on the need for the attention for the unusual not the usual.

So there is a whole set of dynamics that come into place and we go back to these models. Standardized peer to peer hits the bill of allowing electronic order ideally to come in with electronic data coming back but it doesn't fill the need of totally integrating with the rest of the care experience elsewhere. The portal is sort of the Google model so that if there are different bits and pieces of data out there and you want to know what John Perlin's data are and you sort of Google into that, and say, okay, I got that there, got that there, but it doesn't necessarily resolve the issue of getting that order electronically to the lab company. It may have more effectiveness as a viewing engine.

And then there's the third model which actually, potentially, and we are really just learn being this because they are very evolutionary, the RHIOs, where the different entities engaged all with a different interest that happen to synergize and result in greater efficiencies and higher safety, higher quality. So value to each. Each actually brings the adoption curve forward. But each with some specific opportunities and each with some specific challenges. Clearly the RHIO is by far the most complex.

FEMALE SPEAKER: At the risk of opening a Pandora's box here but since you guys brought it up, I think it's important. From the consumer perspective, certainly we want the provider to be able to read our lab results and tell us what the problem is. But we'd also like to be able to easily get that information.

But more importantly, we'd like to know that that information is not going to be used against us. For example, if we think we may have a genetic predisposition to something, I'd like to feel comfortable that I could go in and have that test without becoming un-insureable. I'd like to know that when I've been diagnosed with a life-threatening illness, that that means that I will still have my insurance, that I won't -- that I won't be taken off the ropes.

It's those fears that I think are preventing us from adopting anything electronically. Because there are so many punishments in place right now, and I think that ideally probably everybody here at the table would like to go forward with electronic medical records. We'd like to go forward with personal health records but how do we overcome those fears and those punishments? And that does open up a Pandora's box but I think it needs to be said.

SECRETARY LEAVITT: Helpful conversation all the way around. I know we have to move on. May I just ask this -- a lot of the questions I raised I suppose will be disposed of by the market. People will decide how they want to use it. There'll be policy questions that are raised by -- when the information being available. In terms of the work group doing your job, do -- you don't need necessarily to have any guidance on which of these we're moving towards. You simply -- once you have created the standards, ultimately the market will find its way into a vision. Am I correct?

Or do you need to have guidance at some point on which of these --I should use this as an opportunity to say if there's been a discussion thus far made clear, we have not selected one vision or the other. That there's nothing cooked about RHIOs or there's nothing cooked about portals or peer to peer. This is it.

LILLEE GELINAS: That's correct.

DR. PERLIN: I think your phrasing is very correct. But our goal -- your broad charge to us was to speed the adoption of electronic health records and in fact, RHIOs offers some advantages but there are very few of them. So -- every lab test comes back as electronic data, how do we capitalize on that? So I think there is a market dynamic that helps them to move forward and ultimately the market forces will help determine which are best approaches.

SECRETARY LEAVITT: Could I ask in conclusion, and we'll go on to the next discussion for your assessment on how optimistic are you, you can meet the year deadline to come up with your specific and general charge?

DR. PERLIN: I think it's important to hear Lillee's comment on this. Let me offer the first part which is that I'm a born optimist. I'm very enthusiastic about this moving forward. I think Al raised some concerns that patients may have but I just called attention to a great advertisement by the Markel foundation that has a guy on the ladder falling backwards and the bubble above his head says "Quick, in 3 seconds tell your doctor about your entire health history."

So I think the compelling good is that we can do better. We can be safer. We can offer higher quality. We can improve the efficiency and in fact, with these sorts of systems we can protect the privacy in ways that you can't assure with faxes back and forth and phone calls and voice mails. So I think there are challenges out there but I think your question is that we can definitely gain momentum in a variety of these approaches and learn over that year and Lillee, you represent the private --

LILLEE GELINAS: It's well put. I just -- we've reached this point in order to have this debate, this fast. I want to point that out to you. That's one thing.

The second. That's right. And when you look at these, two are evolutionary, one is revolutionary and we've got to decide which one we are going to land on.

But there is some very important words here that John and I spent a lot of time on and that is on -this is slide 5, optimal model versus alternate model. You don't see better, best, good, you see
optimal for the goal, for the charge, and alternatives. And in the short period of time where we
have been meeting we haven't been able to contemplate further but we know that we have reached
consensus on this part.

SECRETARY LEAVITT: Is it not -- is guidance now --

LILLEE GELINAS: Yes, please.

SECRETARY LEAVITT: One of the principles we have been operating on is that there is the pure vision and the immediately available. And that we have not wanted to hold up the immediately available in deference to the pure vision. And to the extent that one represents the pure vision and would in fact hold our ability to capture the immediately available, I would counsel that we -- if that's the evolutionary, and I don't know which one of those that argues for but as a principle I think it's a sound principle and I would ask members of the Community to comment on that if there is any disagreement about that point.

FEMALE SPEAKER: Thank you. I think it is important to think about that incremental change over time and I think some of what is up there, particularly the peer to peer interfaces lays groundwork to the bigger vision and it really is to get to the standardized part and there is nothing about moving forward to that that would prevent further development of greater ability to share. So I think it is a good starting point.

SECRETARY LEAVITT: Yes, Doug and then we'll go to the next.

DR. HENLEY: Going back to the broad charge of the work group, the two greatest barriers to adoption of electronic health records by physicians and other clinicians are cost and lack of interoperability. The focus of the work group at present on laboratory interoperability, laboratory data interoperability, I think is an excellent focus in terms of immediate results, using any of these potential models.

I think all three models are important and when you go from lab to the entire EHR, all three models have to exist in the system to assure interoperability based upon geography and different types of folks and populations and so forth.

But beyond the immediate focus on laboratory interoperability which I applaud and think is the right focus for right now, we still have to keep the eye on the big ball which is the total EHR and there are other electronic based tools out there that physicians and other clinicians can use to encourage them to move in that direction more rapidly and so as the work group looks beyond the laboratory interoperability, which is important, and will be a driver, we need to look at those other issues as well over time.

SECRETARY LEAVITT: It occurs to me that it's not likely we'll ever reach the pure vision without achieving peer to peer first. There are some natural sequences here that will follow. David, let's go to the next presentation. Thank you. That was a good presentation. Well thought out and we wait with baited breath for your next report.

DR. BRAILER: Okay. Tab 8 is the biosurveillance work group which is chaired by Julie Gerberding and Mitch Roob. With that I'll turn it to them.

DR. JULIE GERBERDING: Thank you. I'd really like to thank the committee. There has been a lot of fast work going on in this group and I think we've moved forward very quickly. Not to mention on this graphic is Laura Kahn who at the CDC side has really been doing a lot of the legwork on my behalf and I wanted to specifically thank her. She is here today also.

We have a great pure vision trying to develop a system that really will allow us realtime national event monitoring and response capability for protecting the public, basically. And the specific charge that's honing on what can we do fast to get us the most essential information as quickly as possible in a format where it may be useful?

That is an important vision and there are many specific steps that we've talked about that have to in order for that to happen. One is that we have to intuit the data needs upfront because we don't have the sociology and the business case that I think we have in some of these other domains.

We also have to get data, and we spent a lot of time in our committee talking about how we would do that. We have to be able to validate the completeness and accuracy of that data and know that we are getting enough in the catchment large enough to really tell us in a sensitive way where events are happening or occurring in the population, and again we have to start with some intuition on that as we go forward.

We need to also have the algorithms that allow us to interpret the data and make information and knowledge out of it and communicate that to people who have to take action, so the functionalities of the system are like peeling back the layers on an onion. It becomes more and more complicated as we go forward.

And I think -- the last aspect of this is to truly evaluate the utility of this kind of an approach when compared to many of the other traditional or less electronically based systems, so that we really know what's the value proposition here and how much further along will we be nationally as a consequence of this than if we improve some existing systems or took on a more limited approach to this. And there are controversies about that so I'm just trying to own them upfront.

Our work group so far has been focusing mainly on data acquisition. That piece that describes what data, where are we going to get it? How will we get it? How will we handle it when it arrives? And we have made some steps forward in this.

I think we agree that it's important to begin with a minimum data set that most data sources could use and that we arrived at actually a fairly consensus-driven list of the minimum data elements that we think are important. We did this by looking at some systems that have informed us already from New York, North Carolina, the CDC Bioscent-system and Frontline, just to look at what data elements are feasibly collected already. So we have, I think come up both with a minimum set as well as a target set, that we think ultimately we could make an argument or a case that there would be utility in those additional elements but we're not sure the feasibility of getting them and so forth.

We also agreed that it was important to use some sort of data linkage so that at the authorized level people could respond to a potential event by taking the necessary action to investigate it in more detail and protect the public. So while, from an aggregate point of view at CDC, for example, we

don't need to know the names of the people who are involved in this, at some level in the system that information will be critical because individual investigation and action will likely need to occur.

And that we should try to build from existing programs and not start over from scratch because there is already a significant investment in this area and it would make more sense to try to harmonize them and learn from them rather than throwing them out and building something independent or new.

On the recommendations to support these kinds of steps, there are lots of different models about the direction the data could flow throughout the system of people who need to know. For example, we could use the linear relay system where data goes from the source to the local public health agency to the state to the CDC to the homeland security council, etcetera, or a more spoke and hub model where there is a source and simultaneously the data is extended to those authorized to receive it and make use of it. That of course assumes that all of those recipients have the tools to be able to interpret it and put it in context and take action when they receive it.

So it's likely as we start out, there will be some hubs in the system that will have more facility at being able to do that interpretation and creating information out of that data and that those hubs would help service those parts of the system that didn't have that capacity until they developed their own independent capability.

And certainly this is a consistent model that would work very well with the RHIO over time as the RHIOs develop where the RHIO could really be the relay and bring the data into a format that would allow it to be cascaded out to the rest of the people who need to know it.

Understandably this is a violation of the traditional model of data movement through the public health system. Where it has always been a relay system and moved fairly slowly with paper records and telephone calls and faxes and now we're really reinventing the whole approach to data and who has access to them and what order and who knows something before somebody else. In this model, the more fast your interpretive capabilities, the faster you know there is something going on and that will require a lot of work to really be able to figure that out.

There are some open issues on the next graphic that we certainly recognize have to be dealt with. One is the whole issue of standards and how the standards for the public health system intersect with the standards for electronic health records, and I think we've heard many strong arguments here for that harmonization but we just need to decide what they are so that we can move forward and there are very few -- relatively few standards for public health data compared to the data that are in use in many of the existing electronic medical records systems.

There are the usual questions -- I thought that came up very nicely in your presentation about the incentives to participate are really the value proposition or the business model for this. Who will pay for these systems? And who will benefit from them the most as they evolve and emerge and we really have to do more on the sociology and the financing of this, as well as the science to make sure that we understand the value proposition. Intuitively it makes sense and the kind of world we live in where we're thinking about these things every day, but until we really recognize that it has to have value for the contributors and the users at every level it'll be much harder to accelerate the development.

And the issue along those lines of whether or not participation in something that's so vital to protecting the public should be a voluntary activity or something that was either strongly rewarded or required as a condition of citizenship in a sense in the electronic system. So we didn't address that specifically but I think it's important question for us to get some feedback and input on. And I guess the last aspect of this is the decision that we made because of the interest in a speedy start to this that it would make more sense to go broad initially and not deep. So to try to not just in terms of the minimum data set but the expectations from the system and its first iteration to try to get inclusion of as many sources as possible and we are focusing on emergency rooms and ambulatory care settings that are already contained within existing hospital admission systems. Not reaching into doctor's offices right now, or places we have a harder time getting information from. But to go broad and fast and then as we learn more, to slowly add in the depth that we might need to add into the system additional functionality and utilities.

We have a lot of work to do and some very important next steps that Dr. Roob is going to talk about as well as the prospectives from state and local health officials that have had a chance to respond to this already.

DR. ROOB: Thank you, Dr. Gerberding, and thank you to your staff, and particularly to Jeff Wells who has been working on this with us as well. I would just amplify a couple of points. First of all we have not allowed the perfect to be the enemy of the good here. Creating the minimum data set took an enormous amount of effort but having it gives us the what. The Who being the EDs and associated ambulatory care facilities gives us the Who. And the How, moving that data through RHIOs back to CDC for quick analysis gives us the How.

So I think we will meet the deadline that you have articulated reasonably effectively. Let me -- on behalf of -- this issue has -- as Dr. Gerberding alluded to, causes some consternation among the traditional public health folks, and so we have reached out to many in the public health community, particularly at the states, to get their input in terms of how that data moved and I do think on the part of -- on behalf of public health folks around the country, it would be incumbent on me to say that the state health commissioners want that data for people who live in their state to quickly get into their systems. That -- as a former governor, I'm sure you can appreciate that -- the necessity of doing that.

If we go to a RHIO model which frequently is designed around a multi-state facility, that RHIO will have to be able to feed data to multiple state health departments as they feed the data to CDC as well. That is not a insurmountable barrier but it is a key point to keep the state health commissioners onboard in this effort. Thank you.

SECRETARY LEAVITT: Questions or comments. Craig.

CRAIG BARRETT: I'm still infatuated with the Wal-Mart. Lee Scott every morning has the sales of every store in his network on his desk and pricing and what items move and what don't, and I'm trying to always look for the equivalent in the health care system. Because I think that's exactly what you want is within 24 hours the results of the prior day, and when I think about what part of the health care system I think, okay, what part of the health care system already has some form of electronic record keeping or electronic health records which are ultimately searchable because they are big databases and then can't you just take those databases which are spread throughout the US?

I mean if I go to Kaiser Permanente and they deal with 3 million people and VA deals with 5 million people and -- how big a sample do you need from those existing databases to have an adequate measure of a pandemic, something to be able to differentiate between the onset of flu with the first day of hunting season and a real pandemic? How big a database do you need?

DR. ROOB: If I could just respond to that. Just coincidently happened to bring the information from the great state of Indiana here in terms of -- because we have -- been operating this for a couple of years now this. This is daily what the state health commissioner gets. Right, which is that linkup from 41 of our emergency departments and some ambulatory facilities. That flows into her office every day. And then this gives you the alert time a neurological syndrome in District 10. So I think this is maybe what you're thinking about. This exists in some states today.

The problem I think will be that if you get a plane landing and you disburse that population to various -- for instance Chicago, they land in O'Hare, they're going to go to Wisconsin, Illinois, Indiana, Michigan. If you don't pull that -- and that's outside the boundaries of a RHIO. Unless you pull that together, the only person that will see that is going to be Dr. Gerberding because they're going to arrive in emergency departments in ones and twos. By seeing them together, you get that. And that's why it's not -- it's important to do a census of that, not an actual survey. So this is -- is that helpful?

CRAIG BARRETT: Well, I'm presuming you can search by incident type and incident geography? I mean I'm presuming that's what databases allow you to do. So I'd like to see that for both. Nationwide, or then by incident and then geographic by incident as well. My question is just how big a database do you need and don't we already have enough of these existing EHRs in that are searchable today?

SECRETARY LEAVITT: I'm going to ask Dr. Gerberding to respond as she warms up. Yesterday I was at CDC and I had occasion to meet with a team of epidemiologists. And I was basically receiving epidemiology 101. They brought these disease detectives in and began to lay out case studies, and what I'm learning is that, Mitch what you set said is correct. We are talking about finding five in a universe of 5 million and that becomes the place where we want to catch it. It's a sample of 5 million might only require 1,000 different pieces of information but it won't find the five. Julie, am I learning a lesson you intended to teach us yesterday?

DR. GERBERDING: A plus, I would say. I think the part of this also depends -- first we don't know the answer to your question in entirety, and I think it depends on what we are looking for. If we are looking for a few cases of serious food born toxic illness in the population that is raft with people coming in with diarrheal illness every day, we've got to have a very sensitive system with a lot of data elements in it and a lot of trend. Hopefully also laboratory connectivity.

But if we are looking for a signal above background, a sample of the population, for example if we are just looking for an up tick in influenza-like illness in the population, then we don't need to have such a comprehensive set of data elements in the system because the number of events we are seeking for is large. And so it really does depend on exactly what we are expecting the system to be able to define for us.

CRAIG BARRETT: I guess then my question is, is the problem divisible? Can it be partitioned into two pieces? If you're looking for 5 needles in the United States haystack that's one issue. If you're looking for onset of a more common disease or flu or pandemic, which you don't need such a

large population for, and I suffer from ignorance on not knowing how the current system works. All that I know is through examples, there are some pretty sophisticated databases today and I'm just not sure we have an integrated system to search those databases as opposed to starting with some something new. I'm all for building on what we have. That was the basis of my question.

DR. ROOB: And we are -- that's why we will go through the RHIOs, which in many cases have this system existing today. So we won't build this new. This is not a Denovo system. This takes existing data elements and analyzes them more effectively. Thank goodness some company developed a really effective processor for churning through all this data because the amount of data that we capture here is just unbelievable.

MALE SPEAKER: We'd like to you look through more data.

SECRETARY LEAVITT: Lillee and then Jonathan. Do you have a comment?

LILLE GELINAS: Just a quick question, though. You talked about the Indiana report. Does that include veterans? Where is the DOD and VA surveillance in all of this? I don't understand that piece. Is what you described just the private sector?

DR. GERBERDING: I would just say right now the DOD and the VA contribute many of these data elements to CDC in a 24-hour time frame so we are including already a catchment of information from the federal health care facilities in the sort of prototype of the surveillance system we have under development -- the biosense-system.

SECRETARY LEAVITT: Jonathan.

DR. PERLIN: Just a quick comment on some -- what Dr. Roob and Dr. Gerberding alluded to this very traditional relationship of building up from the local community to even broader municipalities to the state and regionally country and you made a comment about the value proposition for all informed. Wouldn't the hub and spoke model, wouldn't the rapid deployment of data to the different elements also serve value? Because isn't it possible that something could be going on in my neighboring community and I'm unaware of it because of the sequential nature? Wouldn't it be available to come back to me and wouldn't that kind of close the value loop?

DR. GERBERDING: We think so. But the downside of this is the reality of our public health system, which is local in many cases means nothing. Where there really is no capacity to make use of the information as it comes in, and so we have to rely on the nearest neighbor or the state to take on the responsibility for some of the local jurisdictions where they just simply don't have the investment to develop the capacity.

Fortunately that's not true in every location. We have some marvelous local health departments large and small that are able to do this already and have been wonderful kind of laboratories for learning how to make this work. But I think we believe the value proposition is there in speed, in sensitivity, and getting the treasured epidemiologists that we do have to be doing something about the problem rather than spending their time acquiring the information and manually looking at it. That can be an automated process and decision tools and algorithms can be built in to it to even warn people without them having to go to the computer to look at the data so they spend their time in the more cerebral modes of action to respond and try to prevent the problems.

## SECRETARY LEAVITT: Comments.

I think if not, let me thank you for that report and the ongoing work. What I, in summary, am hearing is that there is high optimism that you will, by the end of this year, be able to provide what will not be deep, but it will be broad, set of data from existing databases that can in fact be accumulated, assembled to those local health departments who have the capacity to handle and use it and beyond that at the Centers for Disease Control where it can begin to be processed and learned and refined. Am I -- are we on track for the year?

DR. ROOB: Yes. That's correct. Let me just add, and at the states. I would be remiss if I didn't.

SECRETARY LEAVITT: I can't believe I didn't say that myself. Thank you. The system. Very good. What I heard on the electronic health records was that you're going to meet in March. That you've defined some very important questions.

What I heard from our conversation was that we are or still have the pure vision in our sights but there are some interim steps that we can accomplish this year. That at least in my mind, the way it's registered, is if I can get peer to peer, ultimately I can build on that and different models will emerge through the market and that will be defined, but the first step is getting peer to peer with standards that make them -- the data exchangeable. I heard Kevin clearly say it has to be both ways and that success is being able to do it both ways.

I did not have a chance to hear the consumer empowerment work group presentation. I would like to just find out how they feel about their making the time frames we prescribed. Who reported that?

GAIL MCGRATH: Dan and I. Actually, we came out with the feeling that our specific charge is to have a medication record and a restoration summary and have recommendations on that by May. Along with that we felt very strongly there should be consumer principles applied for the privacy and so on. And I think we're feeling comfortable that by May we will have some very definite recommendations on what we can propose, along with that certain population groups that could be tested. For example, a pediatric population possibly, but Dan, do you want to add?

DANIEL GREEN: No. That's pretty clear. I think we are on target for that and Dr. Brailer did emphasize to us the need to nail down the who, what, where, why questions.

SECRETARY LEAVITT: Good.

DANIEL GREEN: Or at least the who, what, where. We know the why.

SECRETARY LEAVITT: I didn't have the chance as well to hear the Chronic Care Work Group. Craig, I have no question about the fact you can deliver it.

CRAIG BARRETT: I'm a consumer of it. I think very similar to the other work groups, we believe that you need to build off an existing base and then leverage what that base and demonstrate that in fact you can increase the quality care at lower costs for people with chronic illness.

And there are examples of -- whether it's the VA or Kaiser or other examples of people that are starting to do this today. So if you want something by the end of the year, it has to be built off of that existing base and probably some sub set of that to demonstrate there is increased quality, decreased cost, increased efficiency. And we had a lot of discussion about carrots and sticks and baseball bats and other incentives. We have a lot of work yet to do in that space.

SECRETARY LEAVITT: I know there is a lot of work going on in the work groups themselves and I want to express appreciation for that. I also want to keep the sense of urgency that I feel in front of you. I've made a commitment on HHS's part that we intend to take these standards and to convert them to rule-making which will in fact empower HHS, specifically Medicare and Medicaid, and other health care entities within HHS to begin implementing them.

I'm still counting on the thought that OPM and the VA and the Department of Defense have the same notion in mind and I'm seeing you nod your head and I'm presuming that means yes. We all want to move forward on this together but the power of this Community is our ability to move the market in a responsible way.

Now I'm having conversations with a lot of private sector, private payer, private provider organizations who feel the same urgency and the power of this will be if we move in concert. But if we wait too long, the opportunity will pass us by and I'm intent on making the time frames we laid out and so if you're feeling urgency, I'm glad. If you're feeling over worked, I'm sorry. But keep it up. David.

DR. BRAILER: I think we have one final component of the meeting, which is the chance for public input. Now I'd ask that anyone who wants to make a comment come to the microphone that is in the front of center aisle. I'll ask the comments not exceed two minutes and I'll reserve the right to call you on 2 minutes and ask that remarks be public commentary and not an advertisement or statement about proprietary products or solutions. And please identify yourself and your organization.

JASON DUBOIS: My name is Jason Dubois, I'm with the American Clinical Laboratory association. We represent companies such as Quest Diagnostics Lab Corp and ARUP Laboratories in Utah and I just wanted to help maybe clarify some discrepancies that went on this afternoon about the EHR work group and specifically, I think achieving the pure vision as Secretary Leavitt has talked about is possible, and one of the steps forward and that's been talked about today, is standards development.

And there currently aren't any standards that have been -- obviously HITSP adopted or -- recognized by the department for results reporting, and an effort is going on today that is a consensus driven effort called e-links that is being housed currently at the California Health Care Foundation that does about 95 -- the current version does about 95% of the top 100 commonly ordered tests. That specific version, version 1.0 was adopted by the certification commission. So an effort is being made, but ultimately would need to be adopted by HITSP and the department, and I think that will be a big driver and certainly part of the specific charge of the work group in terms of getting towards standardized. Now that's just the result side.

As a member of the steering committee for e-links it was our decision to kind of first go at it using the low hanging fruit concept that results in and of itself was difficult. I mean there are 1100 lab tests under Medicare and so results with the first step, and certainly we're very interested in taking

it a step further and going towards lab order entry but it's certainly not there yet. But as you said, Secretary Leavitt, I think going at to the from reaching the peer to peer approach first can help get towards that pure vision and I think by helping advance standards development on that peer to peer and by using a product such as e-links results is certainly a step in the right direction. Thank you.

DR. BRAILER: Thank you.

DR. ALAN ZOCKERMAN: I'm Dr. Alan Zockerman. I represent the American Academy of Pediatrics to the CCHIT interoperability working group. I also co-chair the consumer empowerment youth case committee within HITSP. Of course we're extremely pleased to hear the interest in children because children of course depend on us to build the records for the future.

But we need to remind the work group they grow up into teenagers. We need to confront the issue of when the ownership of a child's record transfers to the child from their parents, what rights teenagers will have within their records.

Many of our members now are sharing PHRs from their EHR systems with their patients and a very unexpected problem is when these are brought, either hand carried or even on web pages to various hospitals and emergency rooms, local security systems sometimes defeat access to them. So we need to worry that whatever we provide to consumers can in fact be used at all of our hospitals when that comes up and also if there are break [unintelligible] mechanisms to get to this in the face of emergencies.

The principles for consumer empowerment are really excellent. But there is one that's missing. In addition to consumers seeing the record and they need to have a right that the people that they show it to will actually use it. And interoperability as a very key function that medlist has to be capable of being imported and used within electronic prescribing.

Also, want to remind the group that some of the current commercial payers are indeed sharing not only lab result values but also ICD9 diagnoses from claims. I know my own payer does this. And this issue of direct sharing from claims data and including lab results to patients needs to be addressed within this process. Many of those portals for lab data are run by hospitals and hospital labs, and there has been a lot of attention to moving data on medication lists between the ambulatory inpatient setting.

We also need to do more to make hospital lab data available within small offices. Many of these web portals can be fully interoperable because XML webpages can be saved and read into an EHR.

And the final thing is I'm very glad there is a lot of attention being given now to portability and this ability to change providers for both EHR and PHR because that's going to be a very critical factor in adoption and reducing the risk of making a wrong decision or risk of a particular provider of record system going out of business. Thank you very much.

DR. BRAILER: Thank you. Are there any other public comments?

CAROL BICKFORD: Carol Bickford from the American Nurses Association. As I was listening to the presentation, there was a discussion about laboratory being the model in the EHR implementation initiative and then pharmacy for the consumer group. So it sounds like we have two silos. Do we?

DR. BRAILER: We'll take your question and steer to the work groups to consider that. I would comment that these breakthroughs are necessarily, at least, segmented in the sense that to create a very clear path for the work groups to find a solution, we had to isolate them but one of the challenges this community has as well as the Office of the National Coordinator and the contractors who work with us for a long-term infrastructure is to ensure we have integrated solution across all the different pieces. But we will take that up. Thank you.

Any other comments?

Okay. Thank you. Mr. Secretary, we're done.

SECRETARY LEAVITT: Thank you. Meeting stands adjourned.

[Whereupon, the meeting was adjourned at 3:00 pm.]